Improving Disease Surveillance in Sierra Leone: A Qualitative Study of Volunteer Experiences with a Mobile Community Event-Based Surveillance System

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ABSTRACT

TITLE: "Improving Disease Surveillance in Sierra Leone: A Qualitative Study of Volunteer Experiences with Mobile Community Event-Based Surveillance systems."

BACKGROUND: With many countries, particularly low-and middle- income countries, not having a sufficient surveillance system, as proved during the Ebola outbreak in West Africa, more focus is being directed towards in community based surveillance (CBS) and mHealth. Although there is limited research, the research that does exist suggest that including the communities and using mHealth initiatives can improve access to information from hard-to-reach areas, and prepare and prevent for epidemic-prone diseases and disasters.

PROJECT DESCRIPTION: Community- Event- Based Surveillance (CEBS) was implemented by the Ebola Response Consortium (ERC) and International Federation of Red Cross and Red Crescent Society (IFRC) in Sierra Leone during the Ebola outbreak. IFRC implemented CEBS to report Viral hemorrhagic fevers, acute watery diarrhea, measles, community death, flood and fire through phone calls and SMS from community based Red Cross volunteers to national existing health structures.

OBJECTIVE: To explore the volunteer's experiences with and perspectives on the community event-based surveillance (CEBS) system.

METHODOLOGY: This study employed a qualitative research design. 62 volunteers in total from 14 different chiefdoms in 3 districts participated in in-depth interviews and focus group discussion.

FINDINGS: The volunteers are motivated to volunteer by wanting to help their community, seeing results and also expecting or hoping for incentives in some form. They believe CEBS has a positive impact on the communities; increase knowledge and change behavior, thus prevents Ebola and other diseases and decreased the mortality. There was immediate reluctance from the communities due to fear, but acceptance increase with sensitization and affiliation to the community. Reporting by phone call and SMS was seen as a quick and simple way of reporting for the areas with mobile network, although challenges with sim registration, cost for charging, distribution of volunteers and movement between areas was identified. The volunteers were reporting beyond agreed indicators, potentially due to lack

for clear information and understanding, and also a high need and expectations from the communities.

CONCLUSION: This study has reported some important perceptions from the volunteers and identified areas that need to be considered when implementing CEBS.

TABLE OF CONTENT

LIST OF FIGURES AND TABLES

ABBREVIATIONS

AWD – acute watery diarrhea

CBDS – community-based disease surveillance

CBS – community-based surveillance

CBV – community-based volunteer

CEBS – community event-based surveillance

CHO – chiefdom health officer

CHC- community health center

CHP- community health post

CHW – community health worker

CUG- closed user group

DERC- district Ebola response center

DHMT – district health management team

DM – disaster management

DMO – district medical officer

DSO – district surveillance officer

ERC – Ebola response consortium

ETC- Ebola treatment center

eHealth – electronic health

EVD – Ebola virus disease

FGD – focus group discussion

HC- health center

HP-health post

HR- human resources

IDSR – integrated disease surveillance and response

IFRC – International Federation of Red Cross and Red Crescent Societies

IHR- international health regulations

INGO- international non-governmental organization

IRC – international rescue committee

KAP- knowledge, attitudes and practices

mHealth- mobile health

MoHS – Ministry of Health and Sanitation

NERC- National Ebola Response Center

NGO- non-governmental organization

NorCross – Norwegian Red Cross

ONS – Office of National Security

ODP- Open Data Kit

PHU – primary health unit

SDB- safe and dignified burials

SIM- subscriber identity module

SMS- short message service

SLRCS – Sierra Leone Red Cross Society

SOP - standard operating procedure

RAMP- Rapid Mobile- Phone Based

UNDP – United Nation's Development Program

VHF – viral haemorrhagic fever

VHV-village health volunteer

VSS – volunteer surveillance supervisor

WHO – World Health Organization

CHAPTER 1- INTRODUCTION & BACKGROUND

With the rapid development in technology the recent years, the way we are connected and the way we are communicating is changing. With improved access to mobile phones and Internet for people all over the world, we are seeing new possibilities for how this can be used in the health field, both to provide health services and to receive health information from areas that have previously been difficult to reach. One part of this, which is going to be further explored through this thesis, is to receive information for diseases surveillance in rural areas by the help of the community members and mobile phones.

1.1 Disease surveillance

Disease surveillance systems are used to detect and stop the spread of communicable diseases, and they are an important part of the health systems of all countries. With the increase in international travel, communicable disease control is gaining a greater importance across regional borders. Adequate surveillance systems are crucial for preventing the global spread of communicable diseases (Randrianasolo, 2010). In developed countries where communicable disease mortality has decreased significantly, the objective of a disease surveillance system is to prevent diseases from entering the country and causing an outbreak or re-emergence. In developing countries where there is still a high prevalence of communicable disease, the objective of the disease surveillance system is to detect communicable disease outbreaks early, stopping the spread and associated mortality. To manage this, it is crucial to have a strong disease surveillance system.

There are different types of surveillance. There is passive surveillance, which is regular reporting of disease data by all institutions that see patients and no active search for cases (WHO,2016a). A sentinel surveillance system is when specific units are chosen to identify and report on certain diseases. This data can be used to see trends, identify outbreaks and monitor burden of disease, but because it is from specific detected locations it might not be able to detect rare diseases or diseases occurring outside catchment area of chosen location

(WHO,2016b). As many places have poor access to health facilities, there has been an increased focus on involving the community in surveillance.

1.2 Community-Based Surveillance

In most poor countries, where epidemics seem most likely to break out, there is no systematic disease surveillance in place. A routine surveillance system should be designed to detect early outbreak beyond their sentinel sites and be ready to be quickly scaled up during epidemics (Gates, 2015).

Community-based surveillance (CBS) is an active surveillance process that entails community participation in detecting, reporting, responding to and monitoring health events in the community (WHO, 2014). The CBS system is implemented by using simplified case definitions and forms to identify and report cases to health facilities or others who can respond. The system should be implemented as a routine activity for pre-, mid- and post-epidemic periods to enable early warning, detection and response to cases and to monitor the progress of disease control activities (Ibid). CBS is a simple, adaptable and low cost public health initiative managed by communities to protect communities (IFRC, 2016).

WHO has developed an integrated disease surveillance and response (IDSR) strategy, which has been endorsed by all Member States and is being adapted in the African region to improve epidemiologic surveillance (WHO, 2010). IDSR did initially collect data from health facilities, but is now extended to include community- based surveillance (CBS). IDSR at facility level has been implemented in Sierra Leone, and IDSR is now planned to be implemented at community level (WHO, 2015). ERC and IFRC/SLRCS have filled the gaps of community surveillance through CEBS during the Ebola outbreak in Sierra Leone.

CBS is referred to by different names and can mean different things in different countries. IFRC (2016) relates to CBS as an umbrella term encompassing any surveillance activities that collect community-based health information. CBS refers to two different strategies for collecting community information that are commonly used:

- Community event-based surveillance (CEBS)
- Community-based disease monitoring (CBDM)

Very few studies about CBS have been published, but the research about community surveillance that exist has indeed concluded that the community needs to be involved in emergency response and disease surveillance (Diwan, 2014; Ndiaye,2003; Toyama et al,2015; Oum, 2005).

Toyama et al (2015) piloted an event-based surveillance system at the health center level in Ethiopia, where they used existing volunteer-based community health teams for health promotion and household visits to also report rumors of diseases outbreaks and unusual health events to health posts (HP) and health centers (HC). The rumor was registered in a rumor logbook at the HP, and HP workers would verify the rumor if necessary. If the rumor was verified, it would be reported to the district health office. They found that the acceptability of rumor surveillance was high in the community and that they captured diseases that had not been captured by the routine surveillance system. They reported that the effect of the rumor surveillance was dependent on a functioning structure of the community teams and the willingness to report from the HC. There were also challenges with the response time and the average response time was 3.8 days.

Oum et al (2005) did a pilot study in Cambodia where village health volunteers (VHV) in 7 communes were trained to report suspected outbreak. Standard case definition for 5 diseases and reporting on cluster of cases was used. They found that less than 1 in 20 of the reported cases had contacted a health facility. A household survey was conducted to validate the data reported by the VHV and was, together with outbreak investigation data, was compared with VHV data to find the “true positives”. All cases reported with the exception of one measles outbreak were confirmed to be true. The study concluded that their community-based surveillance system captured more comprehensive and representative data for major communicable diseases and detected diseases outbreaks more frequently and more rapidly than the routine disease surveillance system. They link the high performance to events being important, relevant and relatively easy for local

people to identify, and also the 2-way flow of information by having monthly meetings between health centers and VHV.

Two studies have been found that look at surveillance system from the users perception; one in Ghana(Adokya et al, 2015) and one in Niger (Ndiaye et al, 2003). In both of them interviews were conducted with health facility workers and not community volunteers, but they identify relevant challenges for community- based surveillance systems. Adokya et al, 2015 identified challenges with the core-and support functions, like inadequate resources for surveillance in regards to financial, human, infrastructure and material. The monitoring and follow-up from the district was irregular and the participants also reported challenges with collaboration from the community. The respondents did suggest that reporting became easier after they received mobile phones.

Ndiaye et al, 2003 found that the conventional surveillance system that relies on epidemiologist to visit communities to verify cases was not sufficient for hard-to-reach areas and that the community needed to be involved. It was suggested that the surveillance system should be integrated in to existing community programs and report cases that were locally relevant. Challenges identified by facility health workers to community- based surveillance were lack of disease knowledge and information in the communities, cultural beliefs, lack of access to health facilities and transportation.

Another study in Ghana assessed the surveillance response to 18 suspected Ebola cases and report that there were limitations in the IDSR response, especially from the community level, and mainly regarding poor detection and documentation, with one of the reason being that the volunteers were not trained on EVD identification and response (Issah, 2015)

1.3 mHealth in Community-Based Surveillance

With over 6 billion mobile phone subscribers and 75% of the world having access to a mobile phone, there is an opportunity for using mobile phones to improve access to health care, engagement and delivery of health services and improve health outcomes (Tomlinson

et al, 2013). mHealth or mobile health is medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices, and involves using a mobile phone's core utility of voice and short messaging service (SMS) as well as more complex functionalities and applications including general packet radio service (GPRS), global positioning system (GPS), and Bluetooth technology (WHO, 2011). For the cause of surveillance, mobile phones are often used for data collection and then used together with a data collection software, as for example Magpi(previously EpiSurveyor).

The use of mobile phones emerged within the development of electronic health (eHealth), which means using electronic devices, such as computers, mobile phones and satellite communication, for health services and communication. It has now become its own sub-segment of eHealth. WHO did a global survey (2011) to identify the diverse ways mobile devices are being used for health around the world and the effectiveness of these approaches. One of the approaches looked at was m Health for surveillance, and the African (41%) and South-East Asia (38%) regions had the most mHealth initiatives for surveillance and the use of mobile phones to collect general epidemiological data to prepare for potential disease outbreaks. Studies conducted show improved accuracy, reductions in time and cost, and improved data quality, but more research is requested about the long- term health impact. Tomlinson et al (2013) report that a World Bank report tracked more than 500 mHealth studies, but despite this there is almost nothing known about the likely uptake, best strategies for engagement, efficacy or effectiveness of these initiatives. Bastawrous (2013) states that mobile phones and standard text messaging is proving to be of value in low and middle-income countries with a range of healthcare initiatives, but point out that more rigorous research is required to ensure that healthcare is not flooded with non-evidence based applications, but benefit the patient. Gates (2015) emphasize the need for accurate data and point out that this is not always available because of the chaotic situation that can be in an outbreak, because good technology and training have not been available and because there are no clear rules regarding making data accessible.

There is an increased focus on CBS and mHealth, and several organizations and institutions have already started using mobile technology in disease surveillance, but as the latter says, there are not many studies published about CBS. Particularly not using volunteers in the community with a mobile phone for timely reporting and for reporting on several indicators. House to house surveys have been used for surveillance of vital events (Hartzler et al, 2014;) and particular diseases like malaria, cholera and polio (Hamainza et al, 2014; Santa-Olalla, 2013; Ndiaye, 2003). There are also studies on mHealth surveillance, but which are from the health facility level (Randrianasolo et al, 2010; Adokya et al, 2015; Diwan et al, 2014).

The studies that are published have shown that mobile phones provide an effective means of reporting, but most of them identify a need for more research (Bastawrous et al, 2013; Brinkel et al 2014; Hartzler et al, 2014; Randnianasolo et al,2010; Tomlinson et al, 2013).

One systematic literature review conducted by Brinkel et al. (2014) examined the use of mobile phone-based eHealth approaches (SMS-based, application-based, VRS-based, and telephony-based), which had been implemented for health surveillance in sub-Saharan Africa. Nine studies were included and 7out of the 9 were pilot or case studies conducted in a relatively short timeframe. The systematic review found that surveillance systems with real-time and validated data are crucial for strengthening disease-monitoring capacity in sub-Saharan Africa, and it recognized the great potential of mHealth initiatives to support public health, as well as some general requirements that need to first be in place. The need for the surveillance system should be identified by the national health system, there has to be sufficient infrastructure to implement and hold a mobile surveillance system, there has to be collaboration between policy makers and stakeholders, and there has to be increased awareness in the society. The need for more research and the sharing of lessons learned from pilot studies was emphasized.

A cost-benefit analysis was conducted by Nyeng (2015) for the Norwegian Red Cross, in which paper-based reporting was compared with digital reporting, based on the community- based surveillance experience from Haiti and Sierra Leone. The conclusion was

that, although digital reporting could involve more expenses in the beginning due to the purchase of equipment, the digital reporting system was more cost-efficient in the long-run and also demanded less resources in terms of human resources (HR) and the logistics of delivering paper forms. A study from Hamainza et al (2014) present that although the paper register gave slightly more reports of positive cases of malaria from the community, the mobile phone reporting was more consistent.

Nonaka et al. (2013) conducted a study in Laos, where they assessed whether the establishment of a mobile phone communication network between the community lay workers and the supervisor would improve the quality and timeliness of healthcare provision and vital event surveillance in rural communities. The study reported an increase in timeliness of surveillance report delivery. It also suggest that the mobile phones enabled lay workers to call their supervisor for consultations and the supervisor to give notice to the lay workers about upcoming events. They point out that there are few studies that focus on communication between professional health workers and lay workers. As CEBS in Sierra Leone and CBS in general is based on lay workers in the community detecting suspicious cases and reporting them to health workers for confirmation and response, the surveillance system relies on collaboration and communication between the lay workers and the health workers.

The IFRC has, together with other partners, developed an approach to designing surveys and supporting timely and accurate data collection. This approach is called the Rapid Mobile Phone-Based (RAMP) survey. The RAMP survey is a methodology for conducting digital surveys using mobile phones. Surveys, such as household surveys, knowledge, attitudes, and practices (KAP) surveys and malaria surveys, are usually performed using digital forms on mobile devices, either using Javascript on simple phones or applications such as Open Data Kit (ODK) or Magpi on smartphones. Short message services (SMS) is usually not suitable for surveys, unless they are 5 questions or less. Data is thus reported from a data collector who enters a community, conducts the survey on a mobile device and returns to a central point (e.g. a branch or head office), where the data is transferred to a database either via internet or using a data cable. The RAMP questionnaires have now been

further developed from surveys to direct reporting by SMS from community volunteers to database, and are used for surveillance as they enable receiving timely health data directly from communities (Red Cross, 2013).

IFRC, in their guidelines for early warning for disasters (2012), suggest that when new technology is introduced, it needs to be introduced with a strong level of awareness raising and community sensitization for the community to assess the value of such technology, which is important to considers when introducing phones, as not everyone is familiar with the use of phone.

A lessons- learned review of Community-Based Disease Surveillance (CBDS) was produced by IFRC in 2014. This has not been published, but some notable findings can nonetheless be mentioned. The review concluded that CBDS via SMS has the potential to be a powerful surveillance method and that, as a complement to existing surveillance efforts, it can enable rapid and targeted interventions, which ultimately improve outbreak management, emergency response and long-term health programs, but there are some requirement to ensure efficacy. A CBDS system work best if it is integrated into existing health infrastructure and for SMS reporting to be useful there has to be an efficient response system. It is important with simplicity in data collection and data transfer and training of the CBDS volunteers. The study also suggests that the community is more likely to accept a CBDS system if there is other benefits from it than solely enhanced surveillance.

1.4 Study context

This study was conducted in Sierra Leone and, specifically, in the three districts of Port Loko, Koinadugu and Bonthe, as these are the regions where the Red Cross implemented community event-based surveillance (CEBS) during the Ebola outbreak that started in 2014. Before the outbreak, the surveillance system in Sierra Leone was weak, and the communities were not actively engaged in the surveillance system.

Given the limited amount of research conducted about community surveillance and the complexity of the situation in Sierra Leone due to the long-lasting outbreak of a disease the international community had little experience with, this was a relevant and important context for this study.

1.4.1 Sierra Leone

Sierra Leone is a country in West Africa with a population of around 6 million people. The country is divided into 3 provinces and 1 area: the northern, southern and eastern provinces and the western area (western urban and western rural). There are 14 districts in the country and a district council governs each district. A traditional leader represents each district in the parliament. Each district is divided into chiefdoms, and the country has 149 chiefdoms in total. Each chiefdom has a paramount chief, and several communities, each with their own community leader. There is no documentation found about how many communities exist in Sierra Leone.

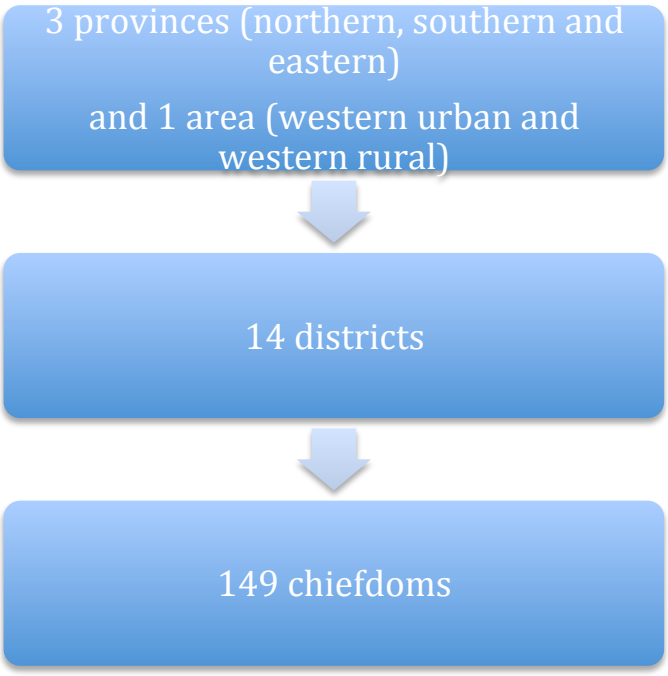

Figure1_Map of Sierra Leone and the country borders. Map info from:
http://www.nationsonline.org/maps/sierra-leone-admin-map.jpg

Between 1991 and 2002, Sierra Leone experienced a civil war that displaced more than one third of the country's population. The civil war and now the post-war rapid population growth are pressuring the nation's environment and natural resources (CIA, 2015). A population census that was planned for 2014 was postponed due to the Ebola outbreak, thus leaving an uncertain overview of where people are living and what the population numbers are. The last census was done in 2004 and it is likely that there have been movements of the population since this. This uncertainty makes disease surveillance challenging. The economy of the country and the status of the health system after the war, also influence the capacity the country has to respond and react to epidemics and disasters.

The Ebola outbreak has even further challenged the already weak economy and health system (CIA, 2016;MoHS, 2015a).

The literacy rate in Sierra Leone is low, making it necessary to consider alternative ways for disease reporting and community involvement than reporting by writing.

2015 literacy rates estimates are:
Total population: 48.1%
Male: 58.7%
Female: 37.7% (CIA, 2016).

Sierra Leone's geographic location, land characteristics, large number of rivers and monsoon climate is also making the country increasingly susceptible to floods, wind storms, landslides, mudslides, wildfires and coastal erosion (UNDP). The risk of flooding also increases the risk of water-borne diseases like cholera. Sierra Leone suffered a Cholera outbreak in 2012 (MoHS, 2015,b).

Sierra Leone has a broad historical, socio-economic and geo-political context of high rates of poverty and illiteracy and is a country still in the process of recovery from crises including the civil war (1990-2002), the cholera epidemic in 2012 and currently the Ebola virus disease (EVD) outbreak (Ibid).

Sierra Leone was one of three West African countries that were most severely affected by the Ebola virus outbreak that started in 2014. The Ebola virus causes hemorrhagic fever, which is often fatal in humans. It initially spreads from animals to humans, and then spreads by human-to-human transmission. Although several treatment options and vaccines are under development, there is currently no treatment to neutralize the virus. Interventions like case management, surveillance, contact tracing, safe burials and social mobilization are therefore of high importance.

EVD was first detected in Sierra Leone in May 2014 and spread quickly. As the epidemic intensified through the summer and fall, an increasing number of infected persons were not being detected by the county's surveillance system until they had died. Instead of being found early in the disease course and quickly isolated, these persons remained in their communities throughout their illness, likely spreading the disease. Thus, a need to support the existing surveillance system and include the communities was identified.

Community Event-Based Surveillance (CEBS) in Sierra Leone was designed late in 2014 by a consortium of Non-Governmental Organizations (NGOs) that made up the Ebola Response Consortium (ERC) and was lead by International Rescue Committee (IRC). CEBS was designed to be an active, village-level surveillance system for EVD that fed into the formal surveillance system at the peripheral health units (PHUs) and district-level surveillance office through the District Ebola Response Centre (DERC), which was mandated during the Ebola coordination and response. The initiative was led and coordinated by the Ministry of Health and Sanitation (MoHS) and implemented through ERC partners in 9 districts, and the IFRC and Sierra Leone Red Cross (SLRCS) in 3 districts, giving a coverage in 13 out of 14 districts. The 14th district in Sierra Leone is the Western area, which includes the urban area of Freetown (IRC,2015).

Since the start of the epidemic, Sierra Leone has had 14124 cases and 3956 deaths confirmed to be caused by the Ebola virus (WHO, 2016). The Ebola outbreak was declared over in Sierra Leone on November 7th, 2015, but already in January 2016, a new case was detected through swab of a deceased woman.

As already mentioned and as demonstrated by the magnitude of the Ebola outbreak, Sierra Leone is vulnerable to epidemic diseases and disasters. Another vulnerability, which is a consequence of the Ebola epidemic, is decreasing rates of vaccination as the health system has been overwhelmed. This has led to an increase in measles (UNICEF, 2015). Measles is a highly contagious viral disease and one of the leading causes of death among young children (WHO, 2015).

1.4.2 Health system in Sierra Leone

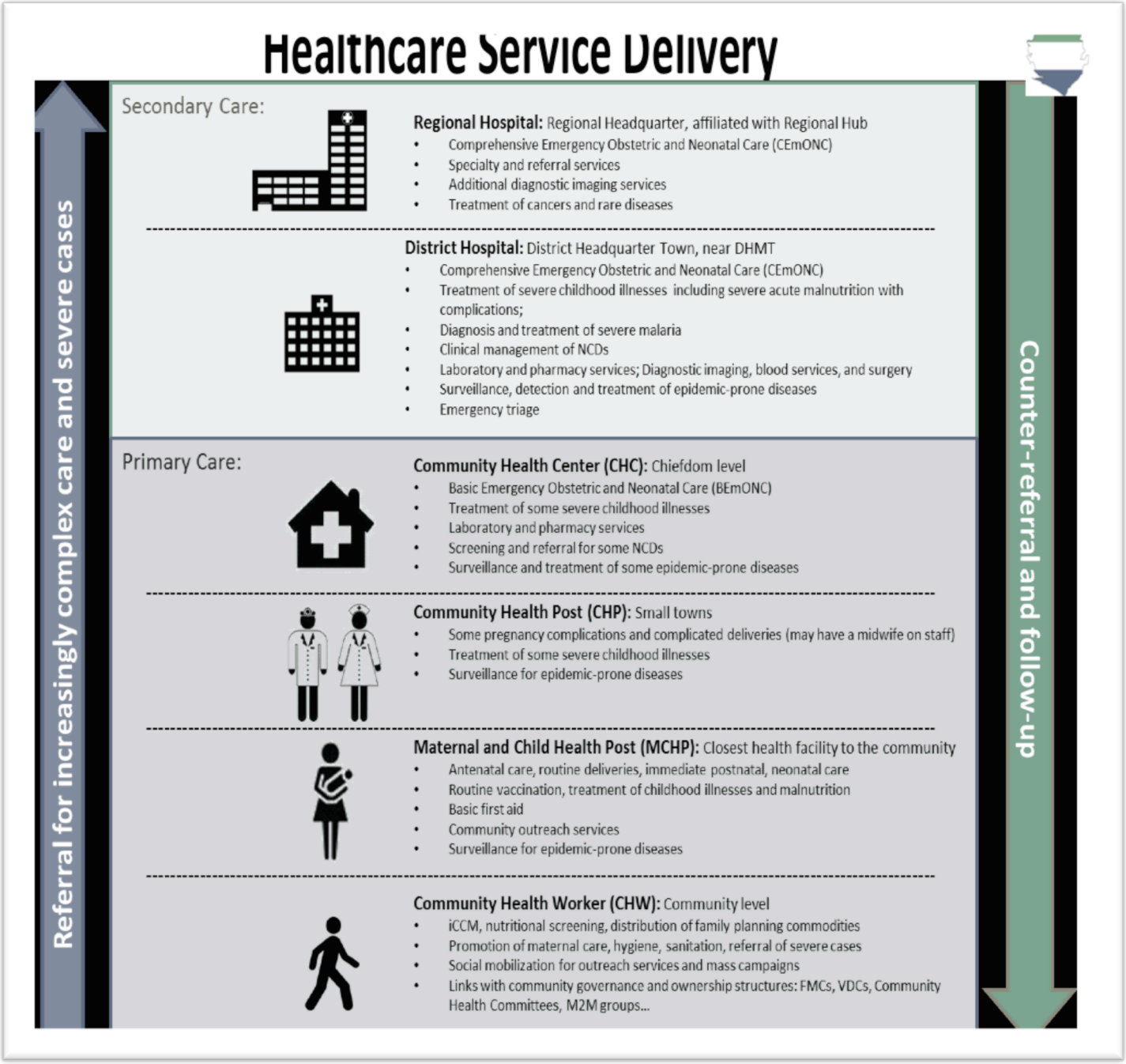

Figure 2_structure of health services in Sierra Leone (MoHS, 2015).

Figure 2 illustrates the health service structure of Sierra Leone. The community level is where CEBS is implemented, but with close collaboration and reporting to the Chiefdom Health Officer (CHO), who is responsible for the health services in the chiefdom. The Primary Health Units (PHUs), which will be referred to in the findings chapter, include the Community Health Center (CHC) and the Community Health Post (CHP). If a case cannot be handled at chiefdom level, it is reported to the district health management team and transferred to the district hospital.

Although there were improvements in the health system prior to the Ebola outbreak, with increased coverage and access to health services, there were still challenges. Sierra Leone has no post-graduate training program for medical practitioners, there is a shortage of health professionals and 50% of the existing health professionals live in Freetown. This means that the dominant health system work force consists of auxiliary level workers, like the Chiefdom Health Officers (CHO), who are responsible for the health services in their chiefdoms and who are the ones the CEBS volunteers report to (MoHS, 2015b).

The rates of undernutrition in the country decreased before the Ebola outbreak, but the level of child and maternal mortality was still high. Laboratory infrastructure and capacity was largely inadequate and essential medicines were scarce. In general, optimizing quality of care has been a challenge (Ibid).

During the Ebola outbreak, 96% of the PHUs remained operational, but a 23% drop in institutional deliveries, 39% drop in children treated for malaria and 21% drop in children receiving basic immunization were reported. The Ebola outbreak has led to a decline in the utilization of health care facilities for non-Ebola related health needs, particularly in urban areas such as Freetown, with a much lower proportion of women reporting pregnancy-related care and as much as a 90% drop in family planning visits. This decline is due to a number of factors, such as absence of trusted health staff, loss of confidence by communities in the health system and safety-related reasons. As the health system is constrained and vaccinations are limited, there is a high risk of possible outbreaks of vaccine-preventable diseases, particularly measles, and also a surge in malaria cases and

deaths, acute malnutrition, and maternal-newborn deaths due to home deliveries (MoHS 2015a).

The health system in Sierra Leone was already facing challenges before the Ebola outbreak, and is facing more challenges from the consequences of the Ebola outbreak. This proves the need for a sufficient surveillance system, but it also suggests that the need in the country also reaches far beyond the need for a surveillance system.

The Ministry of Health and Sanitation (MoHS) and partners developed a health sector recovery framework and plan in 2015 to strengthen the health system again.

1.4.3 Red Cross and CEBS in Sierra Leone

The International Red Cross and Red Crescent Movement is the world's largest humanitarian network and provides protection and assistance to people affected by disasters and conflicts. The Movement is made up of almost 97 million volunteers, supporters, and staff in 186 countries and has three fundamental elements:

1. The International Committee of the Red Cross (ICRC)
2. The International Federation of Red Cross and Red Crescent Societies (IFRC)
3. National Red Cross and Red Crescent Societies

The International Federation works with national societies around the world and coordinates and directs international assistance in response to disasters and diseases.
There are 186 National Red Cross and Red Crescent Societies around the world and each National Society are comprised of volunteers and staff. National Societies support the public authorities in their own countries as independent auxiliaries to the government in the humanitarian field, and National Society volunteers are often the first on the scene when a disaster strikes and remain active within affected communities long after everyone else has come and gone.

This unparalleled network of community-based volunteers and staff also plays a vital role in ensuring that care, prevention and preparedness programs are carried out on a day-to-day basis – from visiting chronically-ill HIV patients in Africa to organizing early warning drills in hurricane-prone areas of the Americas. This local presence and community-based approach, coupled with the Movement's global out-reach, resources and know-how, give the Red Cross and Red Crescent an advantage when it comes to responding to the complex situations in the world today (IFRC. org).

Sierra Leone has a national society, the Sierra Leone Red Cross Society (SLRCS). During the Ebola outbreak, the International Federation of Red Cross and Red Crescent Societies (IFRC), was in Sierra Leone to support SLRCS with the response to the Ebola outbreak. The main support from IFRC was to promote and conduct safe and dignified burials (SDBs), manage the Ebola Treatment Center (ETC) and engage in community mobilization and community event-based surveillance (CEBS). The planning, development and implementation of these initiatives was done by SLRCS with technical support from IFRC delegates.

As described, CEBS was developed by the Ebola Response Consortium (ERC), lead by international rescue committee (IRC) and was designed to identify triggering events where there could potentially be Ebola transmission. They wanted to focus on triggering events rather than case definition for Ebola, as they saw that even clinical workers found the case definition for Ebola difficult. There was also a lot of stigma towards Ebola, so they wanted to avoid pointing out individual people.

CEBS triggering events are:

1. Two or more family or household members become sick or die within a short period of time (less than seven days)
2. Anyone becomes sick or dies within three weeks of taking part in an unsafe burial or washing/touching a corpse
3. Any healthcare worker or traditional healer becomes sick or dies of an unknown

cause

4. Any traveler (or recently returned traveler who is from that village) becomes sick or dies
5. Anyone who was a contact of a suspected EVD case (whether or not they were being contact traced) becomes sick or dies
6. Any unsafe burial or washing of a dead body that took place in the village or surrounding community (This trigger event would alert the surveillance and response team that there might be cases in the near future.)

Due to some delays for the Red Cross in the implementation of CEBS, the number of Ebola cases decreased before the system was implemented. Thus, it was decided to develop the system further than Ebola, to include additional diseases and events deemed relevant for the country by the Sierra Leone Red Cross Society (SLRCS). The standard operating procedure (SOP) for CEBS developed by the ERC was used, but it was modified to include the additional indicators and to be aligned with the existing Red Cross structure. The system was implemented in the three districts of Port Loko, Koinadugu and Bonthe, beginning in July 2015, and now includes reporting on viral hemorrhagic fever (VHF) to capture both Ebola and Lassa fever, acute watery diarrhea (AWD), suspected measles, community death, flood and fire. In Port Loko, there was an increase in suspected Ebola cases and CEBS was rapidly implemented there with the original ERC SOP, reporting on events with the addition of case definitions (signs and symptoms) of Ebola, instead of the modification that the Red Cross had decided on. In Bonthe and Koinadugu, CEBS was implemented with all the indicators from August to November 2015.

The reporting structure and flow of the system remained the same for the Red Cross as for the ERC, but with new names to be aligned with names used by the Red Cross. Thus, CEBS for the Red Cross included community-based volunteers (CBVs) and volunteer surveillance supervisors (VSSs). In the one district trained for Ebola where they used Excel instead of SMS, 2 volunteer data managers were also recruited. In addition to the volunteers, there are implementation teams at the Red Cross branches and a technical working group at the Headquarters.

The recruitment of volunteers is supposed to be done by the Sierra Leone Red Cross staff in collaboration with stakeholders. The Red Cross staff and the community members use the term "stakeholders" consistently to refer to community chiefs, section leaders and chiefdom leaders. The stakeholders were responsible for the recruitment to ensure that the communities felt ownership of the project. The volunteers to be recruited should also be people who belong to the communities. Approximately two VSSs were recruited per chiefdom and 1 CBV per 300-500 community members.

The volunteers are trained to identify people who meet case definition for the chosen diseases and disasters, and trained in the reporting structure and method.

The CBVs collect data in the community and report by phone to their VSS, who, together with the chiefdom health officer (CHO) from MoHS, does an assessment of the situation and decides what level of response is needed. If there is an actual suspicion of an epidemic prone disease, they report to district health medical team (DHMT) who then responds to the case and reports to the National Ministry of Health and Sanitation (MoHS). If there is a flood or fire that is out of control, the supervisor will report to office for national security (ONS).

Both the CBV and the VSS send an SMS report after alerted and assessed. The receiver phone of the SMS is synced to a web-based software called Magpi (formerly EpiSurveyor), through an SMSsync application. Magpi is used for designing questionnaires and collating data. The data coming into to Magpi is exported to Tableau, which is a tool for analysing data and presents it in an interactive, visual way.

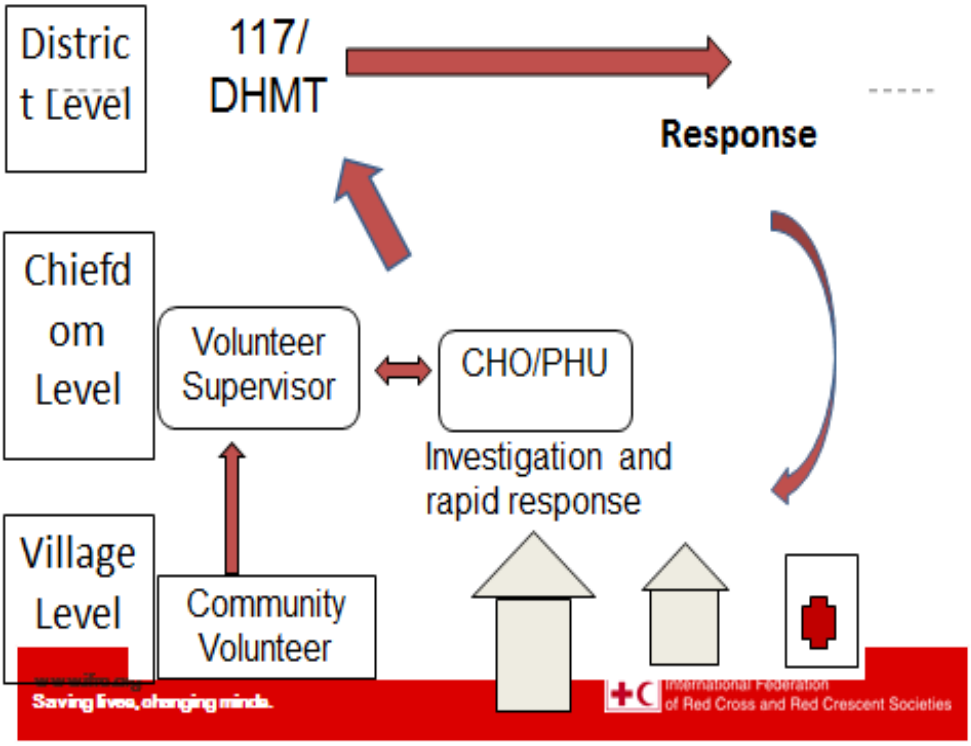

Figure 3_ flowchart of reporting structure

If there are no cases during a week, the volunteers send one report at the end of the week to report zero cases to show that they have been active in their area. The SMS report is written by using pre-defined codes, as shown in the next table.

Volunteer Surveillance Supervisors code		**Community- Based Volunteers code**	
Type of Event	**Reporting Code**	**Type of Event**	**Reporting Code**
Suspected EVD	1	Suspected EVD	1
Acute Watery Diarrhea	2	Acute Watery Diarrhea	2
Measles	3	Measles	3
Community Death	4	Community Death	4
Flood	5	Flood	5
Wild Fire	6	Wild Fire	6
Escalation	Reporting Code	**Gender**	
Yes	1	Male	1
No	0	Female	2
		No person affected	0
Chiefdom level response	Reporting Code		

None Assessment by phone Investigation / visit to community Referral to PHU / Hospital	0 1 2 3	**Age** Age in years No person affected	Number of years 0

Table 1_ SMS codes

The reporting includes which case definition is reported, the gender and age of the reported case, what the response was and if it was escalated to ministry of health. The SMS follows a simple format in which each case definition has a number code, each of which is separated by a hash (#). Explanation follows in the next table.

	Volunteer Surveillance Supervisors SMS	**Community- Based Volunteers SMS**
Explanation	000 # volunteer's phone number # type of event # escalation # response	444 # type of event # gender # age
Example	If a volunteer has reported a person who suffers from acute watery diarrhea, and you have visited the community, notified DHMT (escalation), and encouraged the person to go to the clinic report like this: 000 # 23279219228 # 2 # 1 # 3	If the volunteer has detected a person who suffers from acute watery diarrhea, and this person is 15 year old male, the report is written like this: 444 # 2 # 1 # 15 If there are no events to be reported from the community, send a ZERO report like this 444 # 0 # 0 # 0

Table 2_ SMS structure

The volunteers have all received mobile phones that are registered in a closed user group (CUG). The people registered in this CUG can call between each other for free. They also received reporting paper forms to use as logs and support. All have t-shirts that identify them as volunteers. The VSSs have received motorbikes and receive a certain amount of fuel weekly or bi-weekly.

The surveillance system is still called an event-based system and does entail reporting on events such as community death, flood and fire, but instead of reporting on events for the three diseases that are also monitored, the volunteers learn to report on simple case definitions and symptoms. This combination of event and case definition reporting is something that appears to be rare in published literature, as does the combination of both health and disaster components in one surveillance system. When implementing a surveillance system based in the communities, there might be different types of need and priorities and seeing how this combination is perceived and used by the volunteers is thus relevant. It will also give a view on how a surveillance system can be integrated into different existing community programs beyond health programs.

1.4.4 Using volunteers

Lack of human resources is a challenge in many health care settings, especially in developing countries, and even more so in rural areas of developing countries. Lay workers are often trained and used in various health service programs and for tasks related to vaccination, nutrition, sanitation, first aid, disease surveillance, data collection, outreach, referrals, and health promotion. For the Red Cross Red Crescent Societies, a wide network of volunteers is used for these activities (IFRC. org).

One study done by Nonaka et al. (2013) shows that good communication between the lay workers/volunteers and the national health system or international organizations is important, as the lay workers are the bridge between the health service and the communities. As these workers are not under a paid contract or granted any formal education related to the subject they are working with, ensuring motivation for their work can be a challenge. Their motivation for the work can be an essential contributing factor to its quality. Ensuring good communication and cooperation between the lay workers can contribute to making them feel included and important for the health care that is given.

Another study by Dil et al. (2012) shows that, although volunteers included in the study understood that their roles were voluntary and were motivated by their desires to support

their communities, they all wanted something of material value for encouragement and to show that they are recognized and appreciated.

Within the mobile disease surveillance programs, community health workers or community volunteers are normally used to collect the data in the community (IFRC). For the community event-based surveillance (CEBS) program in Sierra Leone, the volunteers are a combination of national volunteers already volunteering for the Red Cross and local volunteers recruited from the community without being registered with the Red Cross national society. They do not have any formal health education, but receive CEBS training. As described by Nonaka et al, (2013), motivation, communication and collaboration with the volunteers is important to ensure a bridge between the volunteers and the communities. Thus, when evaluating the CEBS program, it is important to consider the perspectives and experiences of the volunteers and, in particular, to address any challenges that they potentially encounter.

1.5 Study rationale

The Norwegian Red Cross (NorCross) and the International Federation of Red Cross and Red Crescent Societies (IFRC) are currently developing community-based surveillance (CBS) system with the use of mobile phones and online databases for data collection. This includes developing guidelines for planning and implementing the CBS systems. After implementing a community-based disease surveillance (CBDS) system in Haiti for cholera and a community event-based surveillance (CEBS) system in Sierra Leone now during the Ebola outbreak response, NorCross and IFRC have gained experience and lessons learned, but this has not been gathered or documented in a structured way. Moreover, little is known about the experiences of the volunteers, who are the system users.

Little experience and knowledge is also to be found in the published literature, thus there appears to be a need for more data about how CBS is working, what is working and what is challenging. The use of mobile phones, SMS reporting and online database registry, compared to paper-based reporting, is also an important topic, as community-based

surveillance (CBS) systems that utilize mobile technology are gaining increasing attention and being increasingly implemented and used in countries and programmes around the world.

It is important to collect data regarding the experience and opinions of the CBS systems users as soon as possible, to support further development and implementation. For CBS to be effective from the start of implementation, which is particularly important in emergency situations, it is crucial that this knowledge and experience is considered as early as possible, preferably before the system is implemented, thus reducing the need for changes after implementation. The primary users of the system are the volunteers. Thus, it is important to enquire about the challenges that they experience within the system, so that these can be identified and addressed in order to adapt the system to ensure that it is user friendly and offers the support that the volunteers and communities need.

Several of the studies that have been published conclude that more research is needed in this field, with respect to both reporting at the community level and the use of mobile phones. Research among the system users is, in particular, recommended (Randrianasolo, 2010, Brinkel, 2014).

The present study has hence explored the volunteers' experiences with and perspectives on the community event-based surveillance (CEBS) system, with the goal of identifying system strengths and challenges.

1.6 Research objective

The objective of this study was to explore the volunteers' experiences with and perspectives on the community event-based surveillance system in Sierra Leone.

1.6.1 Research questions

- Do the volunteers perceive the system to be effective and, if so, to what extent and in what ways? Do they perceive it to be ineffective and, if so, in what ways? Do the volunteers believe it has helped to identify cases, improve response and prevent further transmission?
- What do the volunteers perceive or experience as strengths of the system?
- What challenges have the volunteers experienced, both in regard to the structure of the system and the practicalities and user friendliness?
- What are the volunteers experience with using both phone calls and SMS reporting?
- How do the volunteers perceive the influence of CEBS on the community?
- What are the volunteers' motivations for initial and continued participation?
- How do the volunteers themselves define the purpose of the system, and what do they think it should accomplish to be effective?

1.7 Thesis overview

This first chapter has presented the project background, literature review, rationale, and objective and research questions.

Chapter 2 will describe the study design and methodology. In chapter 3, the study findings will be presented and discussed. Chapter 4 will offer a summary and concluding remarks, as well as recommendations for future CBS programs to be implemented, and recommendations for further studies.

CHAPTER 2- RESEARCH DESIGN AND METHODOLOGY

This study constituted the researcher's master's project at the University of Oslo, Norway. It was conducted in cooperation with the Norwegian Red Cross (NorCross), Sierra Leone Red Cross Society (SLRCS) and International Federation of Red Cross and Red Crescent Societies (IFRC). The study was approved in October 2015 and took place from November 2015 - January 2016. The fieldwork was carried out and the data collection conducted by the student researcher, who was supported by a local research assistant, working at SLRCS HQ, who assisted with participant recruitment and data collection. The research assistant had not met the volunteers prior to the research. The research assistant was initially hired for support in case of language barriers and because of the knowledge of the local context. Language proved not to be a barrier as all participants spoke adequate English. The research assistant contributed as an observator during focus group discussions and some of the interviews.

A qualitative study design and, specifically, conversational data collection via in-depth interviews and focus group discussions (FGDs) was chosen as methodologically well-suited to the research objective of exploring experiences, perceptions and perspectives. The methodological rationale is as follows: The in-depth interviews presented opportunities for exploring the details of personal experience and pursuing in-depth understandings of individual perspectives, while the FGDs facilitated understanding of the range of perspectives and perceptions present among the volunteers, highlighting important differences and similarities, and producing insight into not only what was said, but also the interactions between them The flexibility inherent in this exploratory, qualitative design provided important possibilities to engage in preliminary analytical reflections while in the field, identifying emerging themes and adjusting the data collection accordingly.

This chapter will present and discuss the following topics: the study areas, participant recruitment and sample, data collection, analysis, dissemination of findings, research permissions, and study strengths and limitations.

2.1 Study location

Figure_4. Sierra Leone district map. Port Loko, Koinadugu and Bonthe were the districts where Red Cross implemented CEBS. Map info from: https://mamasalone.files.wordpress.com/2015/03/sierraleonemap.jpg

The study was conducted in various communities in the 3 Sierra Leone districts; Port Loko, Koinadugu and Bonthe, which is where the International Federation of Red Cross and Red Crescent Societies (IFRC) and the Sierra Leone Red Cross Society (SLRCS) implemented community event-based surveillance (CEBS).

The population and terrain varies between these districts, but they are all challenging. Bonthe district is comprised of both a mainland and an island. Two of the chiefdoms in Bonthe are on the island. Boat transportation is necessary to move between the island and the mainland, as well as between some of the communities on the island. Moving between some of the chiefdoms in Port Loko also requires that rivers be crossed by boat. Koinadugu is the largest district in Sierra Leone and is very mountainous.

Population in the 3 districts (beneficiaries)	
Port Loko	453,746
Koinadugu	265,758
Bonthe	129,947

Table 3_ beneficiaries

The communities vary greatly with regard to infrastructure, road network, access to mobile network and access to health services, food, water and fuel. Some of the chiefdoms are very rural, with communities that cannot be accessed by motor vehicles or even motorbikes. Regulated fuel is not available in many of the chiefdoms.

2.2 Participant sample and recruitment

In this study, participants were recruited and selected using a purposive method. With purposive sampling, participants are selected in accordance with characteristics and criteria relevant to a particular research question, with the goal of focusing on information-rich cases. Aspects of convenience, with respect to language and accessibility, determined the sample limits.

The study's target sample consisted of community- based volunteers (CBVs), some of whom participated in interviews and others who participated in FGDs, and volunteer surveillance supervisors (VSSs), who participated in FGDs. It was limited to those who spoke English and resided in areas accessible by car. Within these limits, maximum variation was sought, particularly with respect to age, gender, professional and educational background and chiefdom.

Recruitment was carried out with the assistance of the research assistant, by either calling volunteers from the volunteer database or travelling directly to their communities where they were working or having CEBS meetings. The study and what participation entailed was thoroughly explained, both verbally and in writing via the informed consent document, prior to asking if they wanted to participate. Declarations of voluntary, informed consent were obtained from all participants.

In total, 62 persons participated in this study, 38 CBVs and 24 VSSs. A diverse sample was achieved. Volunteers from 14 different chiefdoms participated in the study. The age range was from 20-45 years old and the participants were students, teachers, farmers, bakers, IT workers, barbers, volunteers who had previously worked for other organizations and some who were unemployed. It was not possible to obtain an even gender distribution in the participant sample. This reflects the fact that 85% of all CBVs and all VSSs, exept 2, in Sierra Leone are male. A total of 7 female participants were included in this study's sample.

2.3 Data collection

In this study, data was collected via in-depth interviews and focus group discussions (FGDs). In-depth interviewing is a qualitative research technique in which individual interviews are conducted with a small number of people to explore, in detail, their perspectives, perceptions and experiences with respect to a particular topic (Boyce, 2006). Focus groups are a form of group discussion that foster communication between the research participants in order to generate data. In focus groups, this interaction is used as a part of the method; instead of asking each person to respond to a question in turn, the

researcher will ask a question, make a statement or suggest a topic for the participants to discuss amongst themselves. This method is useful for establishing a range of perspectives on a particular topic, examining the ways in which group members interact with one another and exploring matters of agreement and disagreement, and similarity and difference, with respect to a particular topic (Kitzinger, 1995). This triangulation of data collection methods provided an opportunity to pursue, via different and complementary approaches, a comprehensive understanding of the phenomena under study

Twenty-two in-depth interviews were conducted with 22 community-based volunteers (CBVs) from 14 different chiefdoms. Five focus group discussions (FGDs) were conducted, 2 with community-based volunteers (CBVs) and 3 with volunteer surveillance supervisors (VSSs). There were 8 participants in each FGD. All interviews and FGDs were conducted by the researcher in English. They were audio-recorded and observations, notes and reflections were written down by the researcher and, at times, by the research assistant, who was present as an observer during some of the interviews and FGDs. The audio recordings were later transcribed for analysis purposes.

A semi-structured, thematic guide was used for the interviews, which began with demographic questions and thereafter consisted of questions about the implementation and reporting processes and the CEBS system itself. All participants were asked all of the questions in the guide, except when they had already answered through their previous responses. Follow-up questions were asked and further discussion probed depending on their responses. The interview guide was adapted after some interviews, based on themes that had begun to emerge and that warranted further exploration. The FGDs were conducted using a guide that was divided into 3 sections: an engagement question that asked the participants to discuss what CEBS is, exploration questions about their volunteer work and experiences with CEBS, and exit questions that provided an opportunity to discuss any additional matters of perceived importance. The interview guide and guiding questions for focus group discussion can be found as appendix 1 and 2.

A number of informal conversations also contributed to the data collection. Throughout the study period, the researcher travelled within the study area and met several people who were affiliated with the CEBS system in different ways: Red Cross staff, volunteers, community members, stakeholders and primary health unit (PHU) staff. It was natural to talk about the CEBS system with such persons, and doing so contributed to a better understanding of the system and context. Some of these conversations have been referenced in the thesis, and these persons were fully informed about the project and consented to participating in this fashion.

2.4 Analysis

Initial, preliminary analyses took place already while in the field, for the sake of reflecting on the data collection as it took place and identifying and following up on emerging themes. Once data collection was complete, a comprehensive, systematic thematic analysis was performed. Thematic analysis involves a systematic process of searching across a data set to find repeated patterns of meaning (Braun et al, 2006). The data set was coded in accordance with topics and themes through a process of constant comparison, subdivision and grouping, in which attention was given to relationships, inconsistencies and discrepancies, for the sake of both organizing and interpreting the findings. Findings and interpretations were discussed with the student researcher's supervisors and student peers for the sake of considering alternative perspectives. Writing formed an integral part of the analysis process, as the researcher moved back and forth between the data set, the coded extracts of the data, and the written presentation and analysis of it.

2.5 Dissemination of research findings

Research findings will be published in the form of this master's thesis and, potentially, journal articles. The findings will also be disseminated to the Norwegian Red Cross, the Sierra Leone Red Cross, and the International Federation of Red Cross and Red Crescent Societies, as this research aspires to contribute to improved understanding of the

challenges confronted by the Red Cross volunteers in implementing and using the CEBS system, and to improve the strategies for implementation and the system itself.

2.6 Research approvals

A preliminary project assessment was requested from the Regional Committees for Medical and Health Research Ethics (REC), which determined that this project was not mandated by the Act on Medical and Health Research and could be conducted without their approval (appendix 4), The project was then reported to the Norwegian Centre for Research Data (NSD) and was approved on October 29th, 2015(Appendix 5). Ethical clearance was also applied for in Sierra Leone, and the Sierra Leone Ethics and Scientific Review Committee approved the study on October 5th, 2015(Appendix 6). Throughout all project phases, matters of informed consent, secure data storage and handling, and participant anonymity and confidentiality have been prioritized. The informed consent document can be found as appendix 3. The researcher took care to be particularly clear about her role in the study as a student and researcher, and to differentiate this from her role as an IFRC delegate for the CEBS project. The ethical approvals and the informed consent document can be found in the appendices.

2.7 Reflexivity

"A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions" (Malterud, 2001).

The International Federation of Red Cross and Red Crescent Societies (IFRC) hires emergency health delegates as technical support for the Sierra Leone Red Cross Society (SLRCS) Ebola response. During fall of 2015, the researcher of this study was the emergency health delegate responsible for the technical support for CEBS, and was thus responsible for supporting the implementation in the Koinadugu and Bonthe districts, and for the monitoring and follow up in all the three districts. Other delegates were there prior

to the researcher and supported in planning and developing the system, recruiting the volunteers and implementing CEBS in the Port Loko district.

Due to this role, the researcher was actively working with the SLRCS in planning and coordinating the implementation of CEBS. This included facilitating, in part, the training of the volunteer surveillance supervisors (VSSs). It also included monitoring and follow-up visits to the districts to meet with the Red Cross district branches and sometimes participate in their meetings with the VSSs. The researcher did not participate in the trainings for the community-based volunteers (CBVs) and did not meet with the CBVs before the research.

While planning and conducting the research, I, the researcher, was aware of the potential significance of this involvement in the CEBS project. There could be both advantages and disadvantages, but I have been aware of the potential biases and I have done my best to identify, acknowledge and manage these throughout all research phases. As described by Malterud, different researchers will approach a study situation from different positions or perspectives, which might lead to the development of different understandings of a particular situation under study. Malterud (2001) is saying that preconceptions are not the same as bias. While they may, if one is uncritical and does not consciously reflect on these, be problematic, they can also provide a potentially richer and more developed understanding of the study area.

As the researcher, my work with CEBS, I believe, has strengthened the research, as I have an increased understanding of the system and the context. I have lived in the country and seen the system develop, and I am familiar with the context the volunteers are working in and thus am able to understand the experiences and perspectives they shared with me in a more meaningful manner than if I was entirely unfamiliar with the local context or system. I am also familiar with local cultural codes and behavior, which I believe is a benefit when communicating in the communities, but I am still very much an outsider, as well, which provided a distance that was also productive for the research. I clearly distinguished between my roles as a researcher and Red Cross delegate, and between the activities

associated with each role, both for myself and for the research participants. I focused on the data and information the volunteers were giving me, and I tried to develop as deep an understanding of their experiences as possible. I made the most of my simultaneously insider and outsider positions, and did my best to manage the misunderstanding and biases potentially associated with each.

CHAPTER 3- FINDINGS AND ANALYSIS

Themes	**Main findings**
Motivation to be a CEBS volunteer and experience of support received	• Main motivation to volunteer is to support the community and see results, receive training and incentives, increase the chance of employment. • Main support for CBV is in the reporting equipment and the supervisors.
Recruitment and distribution of volunteers	• Challenging for the CBVs to be responsible for several communities. • Challenging for the VSS to follow up CBV when there are too many. • Stakeholders in charge of recruitment and little control by Red Cross.
The volunteers perception of training and preparation	• The volunteers felt prepared to report, but have uncertainties around the use of SMS, and what and why to report. • Increased knowledge was reported as the most important outcome of the training. • Practical training found most useful.
The volunteers perception of- and experience with the reporting methods	• Poor mobile network coverage and delays in registration of sim cards and CUG is one of the main challenges with CEBS. • Some have difficulties with the SMS, but most find it to be easier and quicker than writing forms or SMS. • Practical training and guidelines important for understanding.
The volunteers perception of- and experience with the reporting structure and indicators	• Challenging that diseases they find important and relevant in the community is not included in CEBS. • Weak health system and poor access to health facilities, with limited information about purpose of CEBS, seem to lead to high need and expectations to CEBS from the community members.
The volunteers perception of -and experience with the	• Collaboration with- and acceptance from community members was challenging in the beginning, mainly due to fear and anger after the Ebola outbreak. Improved over time.

collaboration and acceptance from the community and the exsisting health structure	• Difference in resources influenced the collaboration with CHOs • CEBS has lead to increased use of health facilities and collaboration between PHU and community. • That the volunteers belong to the communities is reported as the most important factor for collaboration.

Table 4_main findings

3.1 Volunteer motivation and support

As explained in the background section volunteers were recruited from their communities to be in their community and report if there is suspicion of certain disease and disaster, to support the national surveillance system through CEBS. They are recruited as volunteers and are not paid for their work. How efficient and effective CEBS is depends on the work of the volunteers. Thus, knowing what motivates them, what they perceive as the criteria to work as a volunteer, and what they believe is expected of them and what they expect to gain from the volunteering, is valuable knowledge.

When the volunteers were asked about what motivated them to volunteer, they all, in different ways, replied that they want to help their people and community:

"I want to work for CEBS cause I feel for my fellow human beings."

Most of the volunteers are very active in the interviews and the FGDs and give examples of cases they have responded to, interactions they have had in the communities and positive results that they have seen with people receiving treatment. Many of the volunteers were confident that the death rate has decreased because of CEBS and because people are now seeking medical attention earlier, and they seemed proud when explaining this. They laughed happily while telling their stories and said that they are very happy to be CEBS volunteers and that they want CEBS to continue. Although they are talking about challenges, many also say that it is a process and they accept that it will not be perfect in the beginning.

They all described CEBS as very important for the country and for preventing diseases. As one CBV said:

"*I am working for CEBS because CEBS is the answer to prevention for every outbreak. I see it necessary to work for CEBS because that is the answer to the problems of the communities. If I see a community being prone to disaster, I will go there and help them."*

One sentence, in particular, was stated by many of the volunteers, both VSSs and CBVs:

"If we had CEBS before, Ebola would not have spread so much."

This sentence suggests that the volunteers regard CEBS quite highly and have high expectations of it. This study has not collected any systematic data regarding the number of actual cases reported, so it cannot conclude anything about the statistical effect of CEBS, but the perception of the volunteers says something quite powerful about the influence that they believe CEBS has, or could have potentially had if implemented earlier, on their communities. Though only limited research on community-based surveillance in Sierra Leone exists, one assessment report published by the International Rescue Committee (IRC), who was responsible for coordinating the Ebola Response Consortium (ERC), reports that their CEBS volunteers were involved in 58% of the confirmed Ebola Virus Disease (EVD) cases occurring between April 13th and May 20th, 2015. Although it cannot be known if these cases would have been detected without CEBS, it does suggest that many cases are identified through CEBS and supports the statements from the volunteers. As described in the background, previous studies have seen the importance of including the communities and using mobile phones.

This support the perceptions from the CEBS volunteers of CEBS creating change in the community and help identify and report suspicious cases. These aspects of CEBS will be discussed further in the thesis, but these statements are mentioned here for the ways in which they suggest that the results the volunteers are seeing motivate them to continue their volunteer work with CEBS. One VSS, for example, explained the importance of CEBS as

follows:

"From the start of the outbreak, at least in this district, we had only two surveillance officers. Two people covering the whole district. With so many communities, it was very difficult. I think with the initiative of the Red Cross with CEBS, it has actually arrested the case of outbreak if there is any in the future. If this had been implemented before, I don't think the Ebola outbreak would have spread so much beyond our imagination. Actually CEBS has brought the answer in terms of outbreaks. If there was strong community engagement, Ebola would not have spread outside Kailahun and the little community where it started. We are very grateful to Red Cross for bringing up this idea, because I`ve been moving around in the district and people are really, really appreciating the CEBS project. Instead of having just two people going around gathering information from the communities, information is now coming down from the communities. Before it was just information from the bigger places. Now information can come and meet the DHMT and the stakeholders and appropriate action can be taken."

Working for an international non-governmental organization (INGO) is also mentioned as a motivation:

"Most of us have been serving our communities, like teaching, like volunteering without payment, so if there is an opportunity to work for an international NGO as a volunteer, it's very correct to do. So, we have been volunteers for our community before, not for RC, but for the community."

Some participants also described the positive consequences an INGO has on a community with respect to INGOs having more resources than local organizations. Some also explained that the Red Cross has done positive things in their communities before and that they therefore wanted to be a part of it. Some of the volunteers explained that starting out as a volunteer can potentially help them get a paid job in the organization at a later stage. This finding corresponds to a study done by Watkins et al. (2013) who suggest that people volunteer because they see it as a route to employment.

The data from this study also suggest that the volunteers expect to receive more from the INGO than what they would from a local NGO. Several of the volunteers give examples of other INGOs they have worked for or seen in the communities, who pay the volunteers incentives at the end of the month. The Red Cross safe and dignified burial (SDB) teams were also paid, and the CEBS volunteer explained that they wonder why they do not receive incentives from the Red Cross. They describe having been told that the Red Cross SDB team was paid as they worked full working days every day, but the CEBS volunteers also describe doing this and being expected to be available all the time. The issue of combining the volunteer work with paid work is discussed later in the thesis. These findings suggest that the volunteers, being aware that other programs offer incentives, are hoping for- or even expecting to receive incentives, and that this could also have been a motivating factor to volunteer.

The volunteers often gave a long explanation about how they need motivation, before they, but laughed like they all knew what they were getting at in the end; that they need some kind of financial or materialistic motivation. It can be in the form of money, but things with materialistic value, like raingear, radios and bicycles were also mentioned as motivating. Some of the volunteers had received raingear, which they appreciated a lot.

They all said that they understand volunteerism and that they are not asking for salary, but rather some kind of motivation or at least support to manage the expenses they incur while volunteering, for example, things like transport, phone credit, phone charging, and food and drinks while working in different communities or attending volunteer meetings, which are things they are now paying for with their own money. Some of the VSS have also had to pay for their own fuel as there, at times, has been no fuel at the branch as planned.

One CBV explain the challenge with not receiving any financial support:

"..the only thing is this stipend. We tell our supervisor, he tells us this is volunteerism, but every time volunteerism is very, very difficult. We need to charge our phone, there are monthly meetings, we need to move from community to community..".

The volunteers did not want to specify an exact amount and explained that the amount is not important. They gave the impression that it was important for them to make clear that they are not expecting salary and that how much they might receive is not important, as long as they receive something to support their family or expenses, or even to help in the community. One CBV asked:

"..why would I use the money I have for raising my child on meetings?"

That they consistently started these discussions by saying that they know they are volunteers and know what volunteerism is, gives the impression that asking for money is difficult, especially when they have signed up to be volunteers, although it does come up many times, and talking to the Red Cross staff, confirms that this is a topic that has already been brought up many times in meetings and the trainings. They know they have agreed not to receive salary, but they do expect and desire some form of financial support, at least to cover the costs they incur while volunteering with CEBS, as they were not expecting to incur expenses. The findings of a study published by Dil et al. (2012) support the findings of this study with respect to volunteers being motivated to serve their communities and with respect to the finding that that there is, at the same time, some expectation of receiving some type of incentives.

In this study, the volunteers were asked if they had talked about incentives in the training. Several of the volunteers said that they had brought it up and that the response at the training was that they first had to start their volunteer work and that they could then discuss financial matters later. Some of the volunteers explained that the facilitators said that they did not know how the matter of incentives would be handled and that they would bring it up for discussion at HQ. That the facilitators are not, according to what the study participants have consistently described, taking this opportunity to discuss what

volunteerism means and clearly explain that monetary incentives will not be provided, suggests that this is a difficult matter to discuss and that it is difficult to respond to this expectation, as this was something that had been discussed and decided with the facilitators prior to the training and they were aware that there would not be monetary incentives. When CEBS was first planned, it was intended for use during a short period of time only, while the outbreak was ongoing, and the volunteers were supposed to receive cash incentives as a part of a joint collaboration with the ERC rapid Ebola response. The CEBS volunteers under ERC do receive cash incentives. The Red Cross decided not to give incentives specifically because they implemented the system late and developed it further to include more indicators and serve as a long-term project integrated into existing Red Cross community projects, and giving incentives would not be sustainable long-term or be in accordance with Red Cross policy.

That the incentives was first presented, and that other organizations call their workers volunteers and at the same time give cash incentives on a monthly basis, is likely to make it difficult for the Red Cross staff to explain why the Red Cross volunteers do not receive the same, although they should receive in-kind incentives such as raingear and radios. The volunteers knew they would receive this, but not necessarily when. Raingear was promised at one point for a specific date, but was delayed due to procurement issues. The volunteers were then constantly asking for it and were annoyed when they did not get it. It seemed like promising them things created expectations and, when these promises were not fulfilled in a timely manner and their expectations were not met, there was disappointment with CEBS as a whole. A result of this was also that, when the staff met with the volunteers, a lot of focus was directed toward this topic of incentives that could have been better directed to the CEBS system itself. This suggests that a focus on volunteerism, what it means and what the volunteers can expect from the Red Cross should be clearly communicated during recruitment or, at the latest, during the training, so decisions to volunteer are based on accurate information and shared understandings between the Red Cross and its volunteers.

It also suggest that when Red Cross give promises they cannot follow-up in a timely matter, it jeopardies the trust toward Red Cross and CEBS, and that these kind of promises should

not be made if they are not sure to be kept. As the Red Cross movement is also based on volunteerism and motivation by contributing to your community, promising in-kind incentives for motivation might not be the appropriate way of ensuring motivation to volunteer.

The issue of identification was brought up by most of the volunteers. They received t-shirts that identified them as CEBS volunteers. Most of the volunteers do not feel that this is sufficient and explained that they would like ID cards. They explained that this would help them gain trust in the community and that it would also motivate them. To receive a Red Cross volunteer ID card requires volunteer registration, admission fees and participation in an introductory training held by the Red Cross. Most of the CEBS volunteers were not already Red Cross volunteers prior to the CEBS program, and these tasks were not required of them when they were recruited given the outbreak and need for rapid response. The CEBS volunteers therefore can now choose to register as a Red Cross volunteers. The registration, training and printing of ID cards has to be organized by HQ and, from the researchers observations and discussions with the staff at the branches, this has been requested several times but has not happened. The findings of this study hence suggest that all Red Cross volunteers should, ideally, follow the regular registration procedure and that, in the case that this was forgone due to different circumstances, as in this case due to the complexity of the outbreak, it should be carried out as soon as feasible.

A study from Mexico (Alfaro-Trujillo et al, 2011) explains how volunteers reported that verbal appreciation and social events were some of their most valued incentives. Although none of the CBVs from the CEBS study specifically said that these were incentives they valued, they often, through their conversations, described how the VSS came to see them, that the PHU, CHOs and community leaders appreciation- and also the appreciation from the community as CEBS was gaining acceptance and showing results. They talked about this with visible pride and this suggests that the acknowledgement from the community and their supervisors is an important motivation. The community-based volunteers (CBVs) also talked about how their supervisors make them feel good:

"Yeah, I feel good because my supervisor reaches me many times and asks me about work. 'How is the work?' He asks if I have trouble anywhere."

Many of the CBVs talked about how the VSSs come to their communities, ask how they are doing and discuss issues with them. That the VSSs ask how the CBVs are doing and ask if they have trouble, gives the opportunity for the CBVs to talk about challenges with CEBS. All CBVs said that their supervisors come to see them regularly. How often "regularly" is varies and naturally depends on the distance between the supervisor and the volunteers. Some live close to the supervisor and they see each other several times a week and some live further and see each other less. Most of the CBVs said that they see their supervisors once a week, either because the supervisors come to them or because they travel to the supervisors to report an alert. One volunteer also said that the VSS would pick him up with the motorbike and take him to meet other CBVs. These findings, in particular, can be influenced by the inclusion criteria for this study, which required that the volunteers be reachable by car. Access to some communities, as discussed, is challenging and many communities are only accessible after miles of walking. Some VSSs also said that it is difficult to follow up all of their CBVs due to the high number of CBVs they are responsible for.

The CBVs say they call their VSSs for advice when there is a sick person or something happening in the community. This suggests that the CBVs feel comfortable with the VSSs and trust them. The VSSs are the only persons the CBVs refer to in their discussions, which indicates that the VSSs are their link to and support from CEBS, which is an important feature of this CEBS program, especially given its large-scale implementation.

When talking about receiving information from the communities, the volunteers discussed how to approach people and talk to them. Some of the volunteers explained that they did not tell people that they were CEBS volunteers, especially in the beginning when there was a lot of resistance given the fear surrounding the Ebola outbreak, as will be discussed further later, and they would just talk to people. If they heard that someone was sick, they would not tell the family that they would report it or that they wanted to see the sick

person. They would just report to the VSS and let the VSS talk to the family about taking the sick person to health facility.

This suggests that, besides being a support the CBVs can seek advice from, the VSSs also offer support by taking responsibility for uncomfortable conversations and making decisions. Some of the CBVs said that, because they live in the communities they report from, it can be uncomfortable to ask to see a sick person or ask people to take their sick family members to the health facilities if they do not want to. One CBV explained that a mother had been really angry when her child had been reported sick and was made to go to the health facility. When the CBV tried to talk to her after, she had refused to talk, but when the child was cured, the mother was grateful. The CBV thought it was difficult when the mother was angry.

The VSS level has not been included in all of the community-based surveillance (CBS) initiatives found in the literature, and the previous Red Cross CBS initiative in Haiti for Cholera did not use volunteer supervisors. The community-based volunteers, in this Cholera program, sent SMS reports directly to the database and were then called by a member of the Red Cross staff to verify the reported case. It is possible that, with only one level of reporting, it could be easier for the volunteers to clearly understand how to report and also easier for the Red Cross to follow up. It could also give less risk of misinterpretation and miscommunication, as there are less people involved.

On the other hand, as will be further discussed later, the data suggests that the supervisor level, to a certain degree, functions as the filter it was intended to be – to filter out cases that do not fit the case definition before being reported to the database – and that it links the volunteers in the communities with the chiefdom health officers (CHOs) and is the main support for the CBVs. In Sierra Leone, there were over 2000 CBVs spread over 3 districts. With such a high number of CBVs, the VSSs become a necessary link between the branch, which does not have the capacity to follow up all the CBVs, and the CBVs.

When the volunteers discussed matters of motivation, they also talked a lot about wanting more training. They explained that regular, refresher trainings would provide more knowledge and motivation. As said before, the volunteers seemed to be motivated by seeing the results of the CEBS program, and they said that they appreciate the new knowledge they are gaining through their work with CEBS. The training will be further discussed in the next section of the thesis.

Some volunteers also explained that the most positive aspects of the training were the food, the phone and the transport refund they had received. Two volunteers had something negative to say about the training, and that was that they had not received a sufficient transportation refund. This supports the finding that material incentives are important for the volunteers and suggests that receiving food and transportation refunds is a motivation for attending trainings, although the training is itself perceived as important. A study by Watkins et al. (2013) also discusses how things like food and per diem are important aspects of trainings and sometimes motivating factors for attendance, hence supporting the findings of this study.

The findings in this section suggest that to support and help the community is the main motivation to become a CEBS volunteers, but that the motivation is also strongly influenced by incentives and the hope of getting employment for the organization. The data also suggest that the logistics and equipment plays a crucial role as motivation and support to continue as a volunteer and for the effectiveness of the system, and that the support system in the implementing organization need to be efficient. It is such matters that most often arose when discussing matters of motivation and support, and this suggest that it is possible that they volunteers cannot properly assess the need for other types of support or motivation when such basic logistics and materials are lacking. It is also possible that the volunteers experience themselves as supported and motivated, but in ways that they do not necessarily label and articulate in terms of support and motivation. Even if they have not said it directly, the data does suggest that the volunteers receive support and are motivated beyond the logistics and materials, particularly by the VSSs.

3.2 Recruitment and distribution of the volunteers

The Ebola Response Consortium (ERC), in the original CEBS SOP (2014), established the recruitment criteria, which say that there should be 1 community- based volunteer per 300-500 population, and approximatey 2 supervisors per chiefdom. The criteria established that the volunteers should belong to the communities and be trusted by the community members, have knowledge about the activities in the community, and have the ability to learn about the triggering events for Ebola and the reporting structure. The volunteer surveillance supervisors (VSSs) should have some kind of health background and/or training and experience from the Ebola response. The Red Cross also emphasized that they should prioritize existing Red Cross Volunteers and strive for gender equality.

The Red Cross district branches had meetings with the paramount chiefs and community leaders before implementing the system, to inform them about CEBS and plan the recruitment, training and implementation. The recruitment was conceived of as a collaboration between the Red Cross and the paramount chiefs and community leaders, but what the researcher observed was that the branches do not have the full overview over who is recruited and why. The branches did not have a sense of how many volunteers were female, community health workers (CHWs) or already active Red Cross volunteers. The paramount chiefs and community leaders were supposed to have most of the responsibility for recruitment as they should feel ownership of CEBS, but from seeing the data and also talking to Red Cross staff, it suggest that the criteria's for Red Cross and the community leaders/paramount chiefs could have been different, and that the Red Cross criteria's was less followed.

It did exist Red Cross volunteers in some of the chiefdoms, but not all, making in necessary to recruit volunteers that were not affiliated with Red Cross already. The District Health Management Team (DHMT) also found it important to recruit community health workers (CHWs), and this was prioritized over recruiting already active Red Cross volunteers in the places where there were some previously registered Red Cross volunteers. Due to the severity of the outbreak and the need for rapid implementation of CEBS, normal volunteer

recruitment procedures, which typically include introductory training about the Red Cross, volunteerism and community work, were not followed. With these different and unique factors influencing the recruitment, the Red Cross could have found it difficult to know what to prioritize and how much to be involved. One staff member from one of the branches described CEBS as a project that HQ initiated and was responsible for and that the branches opinion was not requested. He did not suggest that there was anything wrong with this, but said this to explain why he was not sure about how to follow up CEBS and his role.

Given the influential role of the community leaders and paramount chiefs, it can also be difficult, as an organization, to demand that the Red Cross criteria is followed, as the acceptance from the stakeholders is necessary for the implementation of the program, and most probably also influences the community's acceptance and involvement.

All the volunteers say that the stakeholders – the paramount chiefs or community leaders – recruited them, except for 2 volunteers who said they were recruited by the Red Cross branch. These 2 volunteers had previously volunteered for the Red Cross. Most of the others had not.

The important role of the community leaders and paramount chiefs was discussed with several of the volunteers and one CBV said clearly:

"You don't do anything without talking to the community leader first."

Most of the volunteers say that they were recruited because they were active in- and trusted by the community. The few who did not say this said that they were recruited because they knew about phones and SMS. Some of the volunteers say that literacy was required. Others say that it was not and explain that sending a coded, rather than written, SMS is easier for those who are not literate. Some of the volunteers also say that there have been volunteers recruited to work in areas where they are from, but that these volunteers do not live in those communities now and that those communities are hence without volunteers.

That most of the volunteers talk about how they are accepted by the community because they belong to it supports the importance of community involvement. At the same time, some of the volunteers said that the stakeholders informed them that they should be volunteers, but did not inform them of exactly what CEBS was about until the training. This suggests that, although all the volunteers say they are volunteering for their people and communities, they might also do so because the stakeholders requested it and not because it was something they initiated and wanted themselves. It could also suggest that they were just not sure what they said yes to and wanted to participate in a training to receive something. This has been described in other literature, how the motivation for training is what they receive during the training. The Red Cross staff also explained how many people that were not called for the training, came and wanted to participate. At the same time, this suggest that the community leaders were not sufficiently informed about what CEBS entailed and thus could not inform the recruited volunteers.

The number of volunteers was increased due to the distances between residences, limited infrastructure and difficult terrain in many places, but the data still suggest that there was an uneven recruitment with scarcely populated areas having 1 volunteer responsible for several communities with considerable distances between them, while more densely populated areas might have more than 1 volunteer per 300-500 people, as was the standard ratio for CEBS.

The reason for this can be that it was not communicated clearly how the CBVs were suppose to collect data, thus prioritizing more volunteers where there are more people to follow up than to prioritize distance. The branches, and the community leaders and chiefdom leaders could also have felt that they did not get the permission to recruit as many volunteers as they deemed necessary, thus finding it difficult to prioritize where the need was greatest, The Plan of Action (PoA) and the CEBS budget accounted for a fixed number of volunteers, which was perhaps inadequate as the districts where asking for more volunteers then accounted for. With respect to this topic, one participant explained:

"Another challenge is that the villages are more than the CEBS volunteers. Like, for one chiefdom, we have 60 villages, but 20 something volunteers. So, some volunteers are assigned several villages. So, to go there, we are finding it hard. To every day have to go to all the villages, to go between 3 villages two times in the week to check, it is difficult. It will take time. You will not have time to go to your family, to find food for your family."

Many of the volunteers were assigned several communities and found it very challenging. They said it is difficult to find the time to go to all the communities and look for cases. By spending time on this, there is no time left to work. The distance between the communities is also often large, which makes movement between them challenging. Many of the CBVs explain how they often spend their own money on transportation between the communities. How to collaborate with the communities for identifying cases and reporting is discussed further in section 3.6.

Although being responsible for more than one community has its challenges, having more volunteers to manage and follow up also has its challenges. CEBS is already a big project with over 2000 volunteers. There are many volunteers for the Red Cross to follow up and many CBVs for the VSSs, which is a challenge that the VSSs discussed in one of the focus group discussions. The number of CBVs per VSSs varies greatly, with some VSSs supervising only 10 CBVs and other VSSs supervising over 100 CBVs. This variation is due to the population of the chiefdoms as there were recruited 2 supervisors per chiefdom and this number was not adjusted according to number of CBVs. Some of the VSS are finding it difficult to follow up all the CBVs and might suggest that the distribution of VSS should have been more flexible according to number of CBVs and distance.

The data does suggest that the CEBS program could possibly benefit from increasing the number of volunteers; one CBV in each community and/or more VSS to follow- up in areas with many CBVs, which is something the Red Cross could account for in a future funding proposal. But, at the same time, the data also suggests that there are possibilities for re-distributing the existing volunteers in a manner that accounts for not only the number of persons in the community, which is that prioritized by the current program, but also the

geographic distance. The data suggest that the number of people a CBV can be capable of following up depends more on distances and road network than the number of people, while the number of CBVs to follow- up from the VSS is relevant to the capacity of the VSS to follow-up.

The number of volunteers that should be recruited also depends on how the CBVs are expected to collect and report data and the level of response and follow-up expected of the VSSs. If the volunteers on both levels – both CBVs and VSSs – are expected to assess and confirm all cases reported, it requires more movement from them than if they can trust reports from CBVs in the case of supervisors and reports from community members in the case of CBVs, and/or if they can assess over phone rather than in person when reporting to CHO. As will be discussed later in the sections about reporting indicators and collaboration, the volunteers are reporting more than the indicators they were trained on, which influence the movement and the workload. This also suggests that the volunteers are not entirely sure of what they are expected to report. Conversations with Red Cross staff in Sierra Leone suggest that they are unsure as well. This can be due to the complexity of the situation as explained before, but also due to the lack of experience with CEBS. In general, CEBS is a new initiative and neither the SLRCS nor IFRC staff had much experience with this form of community-based surveillance.

3.3 Training and preparation

The VSS received 2- days training together with the CHOs, by Red Cross (RC) staff from the technical working group at HQ and the district branch. The CBVs received 1- day training, from RC staff together with the VSS and CHO in the relevant chiefdom.

When asked what they think about the training, the CBVs all said as a first response that the training was good, except the volunteers in the district who were trained on Ebola, who said they had been promised more training and were still waiting for this. When asked to elaborate on their thoughts about- and experiences with the training, the CBVs, and particularly those who came from the two districts where they report on more than Ebola

and do so using SMS, elaborated while the others mostly focused on the training they had not yet received. The ones who elaborated said that they appreciate learning about the different diseases. They explained that neither they nor the community members knew about these diseases before. Others explained that they are very happy to have learned about how to prevent flood and fire from spreading.

The volunteers said that understanding of - and knowledge about disease and transmission, as well as disaster prevention, has increased amongst the community members. Activities to clean the environment and prevent fire have been initiated in several places and, in some communities, CEBS volunteers have established Red Cross groups in which they discuss and plan activities to improve the environment and health of the community. One CBV suggested that the community members now know their community better, which is an important factor for good collaboration and involvement, and, hence, good surveillance:

"CEBS has influenced the people to know the important work of Red Cross. And influenced our people to know some of the diseases that are in our community. CEBS has also influenced our volunteers and supervisors together with the community members to know our community better".

The data suggest that there was a lack of knowledge about diseases, disasters and prevention in the communities and, regardless of what information the volunteers found most useful from the training, they all appreciated receiving new knowledge for themselves and that they could share with their communities.

When asked about the teaching methods in the training, they explained that they found the practical methods and training most useful. Specifically, these included things like role-play, working with illustrations and the practical training for sending the SMS. Most of the volunteers said that the matter of how to send the coded SMS was clear because they had practiced it in the training. Two volunteers said that they had not practiced it in their training and did not know how to report. One explained that this was because the SIM cards were not yet registered and one explained that they did not have Sierra Leone network in

that area and had been told that they could not report by SMS and had to find another solution. One volunteer also explained that the reporting was clear during the training, but, because the SIM card was not working after the training, he had not been able to report and therefore was not sure if he could remember how to do it correctly now.

Regardless of challenges with sim cards and network, this data support the need for regular refresher trainings to ensure that the volunteers know how to report, even if they have not had recent cases to report, and suggests that practical training in which they actually try to report by SMS is the most efficient way to ensure that they understand how to send the SMS and are likely to remember once they are working. It also suggests that there is a need for an alternative solution in the areas where there is no network, instead providing the volunteers in these areas with only half of the training and no concrete solutions for how they should report.

During the interviews, most of the CBVs said that they clearly understood what they should report and how, but 2 CBVs mentioned that other volunteers had found it difficult:

"What I observed during the training, for some of us it is more easier. But, along the way, we get something missing. Just like what my brother is saying here, we need something like refresher training. Along the way, we have people who are not too much literate. It is not so easy for them to send this message through text SMS. We need another training for them to understand properly how to use the phone and how to send the SMS to our headquarters and Magpi."

Challenges with reporting were discussed more extensively during the focus group discussions (FGDs) amongst the community-based volunteers than in the individual interviews. That most of the volunteers interviewed individually said there were no problems with understanding the reporting methods, at the same time that challenges were brought up during the FGDs, suggests that the way of reporting, especially regarding how to send SMS, was not clear to everyone, and that the participants were potentially more comfortable discussing this in a group setting in which others agreed than when they were

alone. Many of the CBVs also explained that they have not reported any cases yet, which can be another reason for their response; if they have not reported any cases, they do not have experience with reporting, and thus have not experienced any difficulties.

The excessive use of community member training by INGOs, and how these trainings are institutionalized and used to measure outcomes more so than provide relevant knowledge and skills, has been discussed by Watkins et al. (2013). The data from this study suggests that the trainings are perceived by the volunteers as important to the communities with respect to increasing knowledge. Knowledge about-, and understandings of how to identify specific cases and report by SMS is described by them as something that they need training, and preferably several trainings, to achieve. Analyzing this data and comparing it with the study by Watkins et al. (2013) suggests that trainings are necessary, but that the focus for training should be on specific skill training with respect to reporting events and methods.

3.4 Reporting methods

The Red Cross expects the volunteers to report both by phone call and SMS. The CBV is expected to call their volunteer surveillance supervisor (VSS) to report any suspected cases that they want the VSS to assess, and at the same time send a SMS to the database, reporting what he alerted the VSS about. The VSS is then expected to call the Chiefdom Health Officer (CHO) to inform him about the case and ask for assessment assistance. The CHO is the one who decides if the case should be reported to the District Health Management Team (DHMT) for response or if the case can be handled at chiefdom level. The VSS send a SMS to the database after responding, to report what type of response was needed and if it was a case that needed to be escalated to DHMT. Both CBV and VSS should send SMS right after alerting and responding.

The SMS is used for data collection and the information from both SMSs should be combined and presented in the analytical visualizing database, Tableau. Currently, Tableau presents cases reported; what type of case, gender, age, location, response and if it was escalated to the DHMT. It also presents number of active volunteers per chiefdom.

In the district not yet using SMS reporting, all the VSSs collect paper forms from their CBVs on a weekly basis instead of the SMS, for data collection, but they still have the immediate phone call to their VSS for alerts.

The CBVs also send zero SMS once weekly to show that they are active in their community if they have not reported any cases that day. If they should still report by SMS to show they are active, it could be discussed to do it biweekly or monthly, as it could be more feasible than weekly. By having regular meetings with the CBVs, the VSSs would see if they are active.

When the volunteers are asked about when they should send the report and why they send it, it is a variety of answers coming; some say they don't know why, some say they know why-and then there are different reasons given for why: One CBV give this answer:

"So, they teach us how we are supposed to go about the information, but why we are sending this information, the purpose of sending this information, some of us, we don't know, right? We don`t know the purpose of why we are sending this information, what they are doing with this information. Whether they will come and help those people or do other things, we don't know. They just told us to go right around our communities and look for those incidents, so we can send to our supervisors and the head office. So, that is why we are sending this information, but what the effect of this information is, we don't know."

Another CBV explained what the believe to be the reason for sending the report:

"I think the purpose of sending this information is because they want to know the health status of our community, or the country, because they don`t want us to have this outbreak again, like Ebola. So, that is why I think they want to know what is going on in the communities."

This data shows that there are differences in the level of understanding regarding why the volunteers report by SMS. This does not necessarily influence how the volunteers are

working. But, as described earlier about how the volunteers are motivated by their perceptions of the positive results of CEBS, it is also possible that knowing why they report would be motivating. As the volunteers appreciated the practical aspects of the training the most, it is also apparent that practical understandings and being able to relate to and visualize their work is beneficial. When the researcher was working as a CEBS delegate, the generated reports from the SMS was sent to the branches on a weekly basis and was supposed to be explained and distributed to the VSS, and the VSS was supposed to bring them to meetings with the CBV. The impression is that this did not happen as planned as none of the CBVs asked in the interviewed in this study had seen a report, although not all of them were asked. The Internet was not working sufficiently for the branches all the time. They all had periods with lack of Internet. Without Internet, they did not receive the reports. This was explained from the branch staff as a huge restraint for following up the volunteers, but from two of the districts, the branch said they had still given reports to the VSS. There could also be other reasons for not sharing the reports. It could be due to the logistical challenges with actually having meetings, reports not coming to the branch conveniently to when the meetings between the branch and the VSS happens, the branch or the VSS forgets or does not understand the report, or it could be something like lack of printer ink. A study by Oum (2005) concluded that the main reasons for the success of the CBS program was the regular meetings between the health facility staff and the community workers and the 2-ways information flow with feedback to what the community members reported. As there are several aspects of CEBS and the reporting that the volunteers are insecure about, one of the important things emerging from this study to focus on is follow-up.

The SMS is supposed to serve data collection purposes and enable follow up regarding how the reported cases were responded to. In other words, it is not itself the response. The data from the interviews with the CBVs indicates that they rely on the SMS for support and response. The CBVs explained that, if they call but cannot reach their supervisor, they send the SMS report immediately, and it seem like some of the CBVs then believe this SMS will go to the supervisor. When asked if they thought the SMS went to the supervisors, many of the CBVs hesitated before answering no, and some said yes first and then changed quickly to

no. That the volunteers are not confident that the SMS does not go to the supervisors, supports the conclusion that some of the volunteers are not certain about why they send the SMS and suggests that more volunteers than those who said this are likely uncertain.

A reason that the CBVs believe that the SMS ensures response can be that the CBVs see that the VSSs respond when they send the SMS. This is supported by the VSSs. During one of the FGDs with the VSSs, one VSS said that the SMS does also provoke response. To illustrate, he said,

"Like yesterday, the HQ called me because they saw an SMS from one of my volunteers and no SMS from me."

Although response is not initiated by HQ where the database is, but rather by the DHMT through the CHOs, and though the SMS is not what is supposed to trigger a response, it seems that it is nonetheless working as a safety net. In the example the VSS gave, HQ called to see why he had not sent a SMS with response information that corresponded to the SMS his CBV had sent to the database. Because the VSS and the CBV had not had network at the same time, the VSS was not aware of the case the CBV had reported. Because he was called from HQ, he then went to the CBV in his community to follow up on the report. The data suggests that the SMS works hence does function as a safety net, but this will also depend on the number of reports coming in and the capacity at HQ to follow up. As they don't necessarily reach the VSS every time they call either, it should not be relied on. If there are many reports, it can be time consuming to follow up all reports and it can exceed the capacity of the data management officer at HQ.

The CBVs responded differently when asked if they would send the SMS before or after talking to the VSS. Some said they send the SMS right away, while some said they wait for the VSS to confirm and check that they are reporting correctly. In many of the interviews, the question about when they sent the SMS had to be asked many times before a clear answer was received. It was at that point that it became known that several of the CBVs had not sent an SMS report yet and hence struggled to relate or respond to this question.

In addition to many of the volunteers not having sent a report yet, one reason for this difference in understanding can be that different information was given during the different trainings. It is also possible that, in some of the trainings, no information or instructions were given regarding this matter, as it was perhaps not one perceived of as important by the Red Cross trainers. It is possible that the VSSs thus decided what made most sense to them and gave instructions to the CBVs accordingly. Since many of the volunteers say that they were told in the training that it was important to report correctly, they regarded the timing of the report as an important matter. What all the volunteers remembered is that they should send a zero report at the end of the week, after 5pm, if they have not had any cases to show that they are active. This is a matter that they lent a lot of attention to during the interviews, and it, at times, seemed like there are more focus on reporting correctly than why they report- or it is just easier and more concrete to relate to than what and why they report. The volunteers could also believe that this was important to talk about during the interviews as they wanted to present CEBS and how they were working in a positive way, which could include showing that they knew how to report. This is discussed more in section 3.6.

With many volunteers reporting that they were told during the training to report correctly, it suggest that this was a focus from the trainers and that more attention was given in the training to how to report correct rather than to the purpose of CEBS at large. The data also suggests that many of the volunteers are insecure about sending the SMS because they have not sent an SMS yet.

This also suggest that their answer to how they wrote the codes related to what they had learned to do or what they thought they should do, and not to their actual experience. Those who knew how to report correctly but had not yet reported at the time this study was conducted might have just memorized that which they learned in the training, and it is difficult to say whether or not this would have manifested in practice if presented with an actual case. Some of the volunteers who had not reported yet said that there had been sick people in their community, but not the type of sicknesses they should report.

As already explained, the community based volunteers, in the FGD, discussed challenges with sending SMS. They discussed how, even if people had phones prior to CEBS, they were not used to using them for sending SMS. Hence, they explained that learning how to send a coded SMS at the same time that they were learning how to send an SMS in general could be especially challenging.

"The next challenge; this technology. We have learned all this information, how to collect the information, how to report, but the technology, we find it difficult. How to send the report? The texting is difficult. We know how to do it, but the way for send the SMS, we find that difficult for some of us. In the village level ,some people are not common with this phones and sending text message..and it was said to do some refresher training."

"People have phones, but they have them to have coverage and to call their friends and family. But text message is another indicator, because you have to click, click, click and look for the different images, like the hash. You have so many difficulties. It is going and click and going this way. That`s why a training needs many days, or a refresher training, so people can understand."

One CBV said that there was some other CBVs in his area that thought writing the SMS was difficult, so he had gathered these volunteers and conducted a "refresher training" on how to write the SMS report with them. The volunteers now understood how to write the coded SMS. This supports the previous findings that suggest the volunteers find alternative solutions to their challenges. It also suggests that, in addition to getting support from their VSSs, the CBVs find support in each other.

Guidelines that used pictures to illustrate the signs and symptoms of the diseases and disasters, as well as explanations for the codes and how to report, was given to the volunteers in the two districts that reported by SMS. Most of the volunteers included in this study described this as a support and said that they look to their guidelines if they are uncertain about if a sick person or an event matches the case definition, or if they are

uncertain about how to write the report. That most of the volunteers say they use the guidelines suggests that, even if they do not remember all the signs and symptoms, they can still report correctly as long as they use the guidelines, and this suggests that the guidelines are an important feature of CEBS.

There are also logistical challenges, which makes it difficult for the volunteers to report by phone. Many SIM cards are not yet registered on the network or in the closed user group (CUG), which was a challenge the Red Cross had with the mobile service provider, which was not able to ensure registration for all the sim cards that was purchased.

Limited network coverage is also a main challenge. Some communities have no network, while others have Guinean network or have one point in the community or outside, sometimes miles outside, the community. Many volunteers found it frustrating that, even when they walked far to access network and did end up finding it, this was often in vain because the VSS was out of the coverage area and hence could not be reached by phone anyway, meaning that they then had to walk to the VSS. Considering this, they felt that it was easier to just go straight to the VSS, rather than going through the effort required to try to use the phone first without any guarantee about whether they would be able to reach the VSS by doing so.

As many of the CBVs have challenges with their SIM cards and/or network, they find it frustrating that they are expected to send weekly SMS reports when they are not provided with a functioning SIM or access to network. One volunteer explained that they were told during the training that, if they did not send the SMS and thereby showed that they were active, they could not be CEBS volunteers. The volunteer want to continue to be a CEBS volunteer and found this very difficult. The CBVs use their private phones to call the VSSs, but they cannot use their private phones to send the SMS, as the phone number has to be registered in the database for the SMS to come through. The private numbers of the volunteers are not registered in the database. The VSSs often send the SMS for the CBVs, which mean that the VSS have to send one SMS per CBV from his own phone each week, and

this create a lot of logistical work for the VSSs. On the positive side, this shows that the volunteers are capable of finding alternative solutions to their challenges.

That not all the community- based volunteers have access to mobile network or a functioning SIM, also make the number of reports coming in from the CBVs and VSSs not equal. It is also seen that the CBVs sometimes send SMS for cases the VSSs do not find necessary to report.

It is not desirable to have too many codes in one SMS as it might lead to mistakes in reporting, but it is worth discussing if the VSS should be the only ones sending SMS, as gender and age could potentially be added to their SMS, giving that the CBVs experience so many challenges with the phones and network. They could still have the phone to call when it is feasible, but would not struggle against the pressure to find network to send SMS. The data could also be more consistent and clear since it would not rely on data from 2 different people. Since the reporting of the case for response should come from the CHO to the DHMT and location should then be informed about, it could be sufficient with the chiefdom ID that comes from the VSS phone number.

Network coverage is something that needs to be thoroughly assessed before implementation. The Red Cross did an assessment, but when the researcher asked the staff about this during the project planning and implementation that the researcher was involved in as IFRC staff, different results were reported about the coverage. That there were areas without coverage was reported, but it was also reported that most communities had a location where the volunteers could go to get network. A more thorough assessment was conducted during the community trainings, but it was still difficult to get a clear overview. A reason for this could be the difficult terrain. As already identified as a challenge by the volunteers, it is difficult to move between communities due to the condition of roads, and the distances are far. It took the Red Cross training facilitators between 14-39 days to complete the community trainings in each district, which gives a sense of the magnitude of the staff and time resources demanded just to reach around the training points in the districts.

There were no concrete alternative solutions in place for areas without network in the 2 districts that were supposed to report by SMS, but the volunteers in the one district that did not report by SMS, had paper forms that they completed and submitted at the end of the week. The volunteers in the other 2 districts also received paper forms as a form of support that would enable them to keep a paper log if they did not have network right away. Some of the volunteers did use these forms to give to their supervisors.

The volunteers were asked what they believed were good alternatives to reporting when without network, and also if they believed there were other ways of reporting that were more efficient or user-friendly than phone calls and SMS. Reporting by SMS versus reporting by paper, for example, was discussed in all the focus group discussions (FGDs) and most of the interviews. Some of the volunteers explained that they thought reporting by paper would be easier since they must walk long distances to access network for calling and sending the SMS. When asked how they could submit the paper reports, they suggested that the volunteer surveillance supervisors (VSSs) could come and collect the forms or that they could send the forms with someone who was going to where the VSS or primary health unit (PHU) were. It was discussed that, by using paper, the report could sometimes reach the VSS faster, but it was also discussed as difficult for the communities that could not be reached by car. Many VSSs would also find it difficult to move around and collect all the forms from the community- based volunteers (CBVs) within a time frame that would ensure timely reporting. Having to collect forms from all the CBVs would also increase the workload for the VSS. In the district where SMS reporting has not been implemented yet, collecting forms every week to be delivered at a certain day was brought up as a challenge and described as a time-consuming activity.

One volunteer suggested that the forms could be sent with people going into the central part of the chiefdom, who could find the VSS there. But, when asked if there are people going there regularly so that times for them to meet with the VSS could be planned, he said that there were not and then suggested that this was maybe not an ideal method of reporting with respect to ensuring response after all. When discussing which way would

ensure the most rapid response, one volunteer said that the VSS could be called for response, but that the paper form could be used for reporting instead of sending an SMS. He suggested this by explaining that the network was so unstable that, even if he could find enough network long enough to call, it did not necessarily mean that the network lasted long enough to write and send the SMS. Many volunteers had to go into the forest or even climb trees to access network, and he explained that it is not safe for the volunteers to stay alone in these places for a long time while waiting for network.

The volunteers have different experience, knowledge and perceptions of the use of mobile phones, but the analysis of all the data collected suggest that, if the volunteers had reliable network in their community and were registered in the CUG, most of them would find reporting by mobile phones to be the fastest and easiest way of reporting, but this depends upon easy access to mobile network and refresher trainings to ensure understanding of what, why and how events should be reported. The data also suggest that a good assessment of network coverage should be done prior to implementation and alternative solutions should be identified and implemented in areas where it is difficult to access mobile network. CEBS was implemented to make it easier to report form rural communities and hard-to-reach areas, but when there is no mobile network, this way of reporting is working against its purpose.

3.5 Reporting indicators and structure

CEBS was implemented as a support to an existing surveillance system in Sierra Leone, which, during the Ebola outbreak, proved to be weak. In the 3 districts where the Red Cross implemented CEBS, the system was used to detect and report suspected cases, while the district health management team was responsible for the response.

In one of the three districts where CEBS was implemented by the SLRCS and IFRC, the volunteers were trained to detect suspected Ebola cases. In the other 2 districts, they were trained on the following additional events and indicators: viral hemorrhagic fever (VHF) as an umbrella term for Lassa fever and Ebola virus disease, acute watery diarrhea (AWD) as a

proxy for cholera, suspected measles, community death, flood and fire. When asked about the relevance of these diseases and events, all of the volunteers explained that they believe these diseases and events are relevant, but they also explained that there are many more diseases and events in the communities that are just as important, and that they find it difficult that they are not trained on and do not have reporting codes for these.

Malaria and snakebites are two things that multiple volunteers identified as the main problems in the communities, which they wish they could report through CEBS, but that there is no SMS code for. This suggests that the challenges and priorities of the community members might be different then what the national authorities and implementing organizations prioritize.

Despite being trained only on Ebola triggering events and the Ebola case definition in one of the districts, the volunteers in this district were reporting on all diseases and incidents happening in the district when this study was conducted. The volunteers said that they needed to report what was going on in the communities. None of the volunteers could give clear answers as to whether they had been told to report everything or if it was their own initiative, but, when asked, they would laugh like the answer were obvious, and say that they could not say no to the community members when they asked them for help.

The volunteers also explained that they were told they would receive refresher trainings during which more diseases would be introduced, like in the other two districts. They had been told this for a few months, but the training was delayed, and this was something that the volunteers expressed frustration about. While waiting for more training, the number of Ebola cases was decreasing and the outbreak was declared over. Other diseases became more relevant, like measles, and the District Health Management Team (DHMT) requested that the Red Cross CEBS volunteers participate in surveillance for measles, which they did.

This data suggests that there is flexibility in the CEBS system and that it can be quickly adapted according to the need of the community or the national MoHS. The challenge with

this flexibility is that the system can easily be overloaded when the existing health system is weak and the community has a high need for support.

The CBVs in the other two districts, who had been trained on more diseases and events, also said that they would call their VSSs for all sick cases. The difference was that most of them said that they knew they were supposed to report only the events and indicators they learned in the training, and these were indeed what they would report by SMS, but they would call their supervisor for advice on other cases reported by and experienced in the community.

Other volunteers, however, explained that the 3 diseases chosen in CEBS were chosen because they were similar to other diseases. They explained how most diseases could lead to fever, diarrhea, vomit, red eyes or rash, and that they therefore could report other diseases under viral hemorrhagic fever (VHF), acute watery diarrhea (AWD) and measles. One example they gave was that they would report malaria under VHF, as they saw this as all kind of fevers.

Others again referred to the signs and symptoms as particular diseases and not as symptoms of the diseases. This can explain why some of the volunteers believed they could report other diseases under the codes for the 3 defined diseases. It suggests that they report according to individual symptoms rather than the combination of symptoms that makes up the case definition for the 3 diseases. That many of the volunteers could not remember all of the indicators suggests that reporting on 6 indicators can be overwhelming, especially when there are several signs to remember for each indicator.

This suggest that there are different understandings between the volunteers about why they have CEBS, and that refresher trainings are important to have within a reasonable amount of time after implementation, together with clear information about why they are reporting on the specific indicators they are trained on. If the volunteers are consistently reporting alternative or additional indicators than those selected by the CEBS program, it can be necessary to re-evaluate the decided indicators and their relevance for the

communities, consider if there are other indicators deemed more important and, in the case that the CEBS program chooses not to focus on matters prioritized by the community, clearly explain the reason for this and attempt to establish a shared understanding with the volunteers.

That the volunteers find it frustrating that what they learned at the training and the codes they have been taught does not cover all the diseases and incidents they want to report, suggests that having the SMS codes controls and filters that which is actually reported into the database and shared with the DHMT. Although some of the volunteers found ways to deliberately report additional diseases using the indicators for the 3 identified diseases, the data suggests that the SMS nonetheless limits the cases reported to the database, thus sustaining the purpose of the CEBS system as one of early warning surveillance instead of a regular reporting system for all diseases in the community. While I was working with CEBS in Sierra Leone, I observed the data coming in to HQ. Compared to the data reported via paper forms and excel, in which all kinds of incidents in the community were reported, the SMS reported data was much more aligned with the diseases and indicators chosen by the Red Cross, which also suggests that the SMS works as a filter. At one time, the DHMT in one of the districts requested to have all diarrhea cases presented in the weekly report they received. At one point they also wanted daily reports about this. This again shows the variation in priorities and needs among different actors, and the need to either specify what CEBS is for or adjust CEBS according to need.

Difficulty remembering several indicators is a finding supported by an assessment done by the International Rescue Committee (IRC). In the districts where the Red Cross did not implement CEBS, other partners did, under the coordination of the IRC. As previously described, they were reporting specific events in which transmission might occur. One of the reason shy triggering events were used instead of case definition was to make it easier for the volunteers to remember. An IRC assessment report in September 2015 showed that the volunteers, on average, could remember 3 of the triggering events that they were trained to report. 50% also reported triggering events that they were not trained on. The most common trigger event that they were not supposed to report but thought they were

was community deaths. Rather, they were trained on reporting deaths related to specific events. This can indicate that the volunteers could not relate to these events and therefore failed to remember them, but it can also support the conclusion that remembering several indicators is difficult.

It is difficult to know how many indicators are feasible and useful, as most studies about CBS systems focus on one disease. In the guidelines for CBS that are being developed by the Red Cross now, having a maximum of 4 triggers is recommended, and no more than 8 to make SMS reporting easy for volunteers (IFRC, 2015).

The WHO, together with the MoHS in Sierra Leone, is developing community-based Integrated Disease Surveillance and Response (IDSR). In the MoHS Basic Package of Essential Health Services for 2015-2020, surveillance is one of the main pillars. CEBS is mentioned as an important initiative during the Ebola outbreak, and the focus for the future is to learn from this experience and integrate surveillance into routine information and surveillance systems, with IDSR being mentioned as an initiative planned from 2008, but that is not yet implemented (MOHS, 2015b).

As IDSR is planned to be rolled out nationwide, how to align and/or integrate IDSR and CEBS was discussed in surveillance meetings and workshops while the researcher was working in Sierra Leone and conducting this study, but the plans were not finalized by the time this study was completed. IDSR is planned to report on 10 indicators: acute flaccid paralysis (polio), acute watery diarrhea, clustered deaths, guinea worm, maternal death, measles, neonatal tetanus, neonatal death, suspected Ebola and yellow fever (MoHS and WHO, 2015b).

The suspected Ebola case definition in this IDSR program is the community level case definition that was in use when the outbreak was declared over. This case definition was:

“Any sick person with fever AND bleeding from any body part (mouth, nose, eyes, genitals, etc) OR Sudden death with history of bleeding from any body part (mouth, nose, eyes,

genitals, etc)".

The case definition the CEBS volunteers were trained on during the outbreak was:

"Fever + 2 or more symptoms: vomiting, fatigue, headache, muscle pain, unexplained bleeding, stomachache and/or diarrhea".

This research started around the time that the case definition changed, and when the CBVs were asked what the case definition for VHF was, most of them responded with respect to fever and two of the other symptoms they had learned. Some of them did not even mentioned fever, and many did not mention unexplained bleeding. In the focus group discussion with the supervisors, the correct case definitions were recalled for all the diseases and the supervisors could also answer what the new case definition was, but since this was a group discussion, it is not possible to say that everyone knew this.

All the 3 branches in the districts were informed about the new case definition and told to inform the supervisors who were then to inform the community- based volunteers. The data suggests that either this information did not reach all the CBVs or that they have not understood it, or forgot it. Regardless, this suggests that the information did not reach and register with the volunteers as it was supposed to. It could be because the new case definition was not understood by the branches or the VSSs and was hence not communicated to the CBVs. It could also be because it was difficult to communicate this information to all of the many volunteers, both VSSs and CBVs, given the poor mobile network and road infrastructure. Regardless of the situation, these findings suggest that there might be a need for more organized meetings and information dissemination when there is a change in the system. The system will not be flexible if not all the volunteers can receive information about and adapt to the changes. With regular refresher trainings, as the volunteers are requesting, there is a more organized arena available in which changes and adaptations can be presented and adequately taught.

Another reason for not using the new case definition could be that most of the confirmed Ebola virus disease (EVD) cases did not present with bleeding. There was, during the outbreak, a lot of focus on communicating to the population that not all positive Ebola cases presented with bleeding, and this could have worried the volunteers that they would miss cases if they only reported cases when bleeding occurred, as they did say, many times, that they are worried about not reporting correct. Moreover, the frustration that the volunteers expressed with respect to already feeling limited in what they could report suggests that they would not be positive about adopting even more limiting case definitions.

As said before, many of the volunteers said that they used the guidelines when they encountered a sick person, for the sake of confirming if the person exhibited signs and symptoms that should be reported. They were not given new guidelines when the case definition changed, so if they were looking to the guidelines for support, the guidelines would still have the previous case definition.

This discussion about the new case definition and the initiative of IDSR also demonstrates the importance of being aligned with other initiatives in the area when introducing a program like community surveillance, for the sake of avoiding duplication. Due to the severity of the Ebola outbreak, the weakness of the existing surveillance system and the delay in implementing IDSR, it was necessary to implement CEBS for Ebola. With the decrease in cases and the increasing focus on implementing IDSR in the country, the Red Cross's decision to implement more indicators and the data produced by this study that shows that the volunteers are reporting beyond their intended indicators, including some of the same as IDSR, suggests that the Red Cross CEBS system can evolve into an IDSR system, thus constituting a long-term support to the existing health and surveillance system.

Another interesting study finding was that, when the volunteers were describing what they were reporting through CEBS, most struggled to pronounce viral hemorrhagic fever (VHF). This suggests that, for the volunteers, VHF was potentially just some words they had learned and not a disease they could relate to. More questions about this were then asked in subsequence interviews with different volunteers. For example, they were asked questions

about what VHF was and how it was related to Ebola. This provoked different responses, but what was surprising was that several of the volunteers did not think that Ebola was a viral hemorrhagic fever. Some of the CBVs, for example, explained that they were not supposed to report on Ebola and that they had not learned about Ebola in the training:

"Ebola is actually not part of our program"

VHF was used in CEBS to include both Ebola virus disease and Lassa fever, but the data suggest that using this terminology makes it more confusing for some of the volunteers. That some of the volunteers could not pronounce VHF, were unable to recall all of its signs and symptoms and did not know that Ebola is one form of VHF thus suggests that, rather than capturing both Ebola and Lassa fever by using VHF as a common term, this led some of the volunteers to believe that they were looking for a different disease. This does not necessarily have any consequence as, if they remembered some of the signs and symptoms or used their guidelines to determine which symptoms they should look for when deciding whether or not to make a report, they could still report correctly. But, being able to relate to and visualize the diseases they are looking for will likely make them more aware and their reporting more accurate and effective. It is reasonable to believe that many of the volunteers have seen a person with Ebola and Lassa fever, or at least heard about the diseases, and that they can thus relate more to these names than to VHF, as is the case with, for example, measles. When many of the volunteers were asked about the signs and symptoms of measles, they described the rash, runny nose and other symptoms in a way that suggests they have seen children with measles and can visualize it.

For the WHO's IDSR program, "suspected Ebola" is used as a case definition instead of VHF, which, from the data, seems potentially easier for the volunteers. As IDSR is to be implemented as a part of the MoHS's regular surveillance strategy, and as CEBS potentially need to be integrated into this, using the same case definitions and ensuring that the volunteers know that they are looking for the same cases could be important.

On the other hand, one CBV provided a good rationale for not using the term "Ebola" or asking people about Ebola specifically:

"Maybe the name we say to people, we have to be careful. When you talk about Ebola, people got fear, so to transform it, it's called VHF (Laughing). People are scared of Ebola. Whenever you talk about Ebola people run away and say "they want to kill us again". But, if you say VHF, they will come closer. So, from there, from the signs and symptoms, we will see if this is Ebola and we will report, but we cannot say 'Ebola' (laughing again).

This explanation provides important insight into the feelings in the communities and will be discussed further in the next section about collaboration and acceptance from the community. This description also shows how much a word can mean and how it can influence the relationship to the community and the information they will give. There can be pros and cons with using a particular case definition, and what these findings suggest is that the case definition used is an important aspect to consider, as it may have significance far beyond the words used to describe a disease.

The data from this study suggest that the extent to which and how the volunteers remember the indicators varies greatly. Some remember all the 6 indicators and case definitions with signs and symptoms, while others don't remember all the indicators or remember incorrect indicators, or they do not remember the case definition (signs and symptoms) but can say all the indicators. Malaria is often added to the indicator list or recalled incorrectly and in place of VHF. More volunteers remember the 3 events (community death, flood and fire) than the 3 diseases, which also seems to be related to the use of terminology. As with VHF, volunteers also have trouble pronouncing acute watery diarrhea (AWD). Some just call it diarrhea, but then have difficulty separating VHF and AWD as they both have diarrhea in the case definition.

This variation is interesting and it is difficult to speculate with certainty about the reasons for it. One reason can be that the background and previous experience of the volunteers' influences how they relate to the indicators, and that the terminology of the indicators used

is too complicated. Volunteers with no previous professional experience with health have most likely not heard the terms VHF and AWD before the training and might find it difficult to relate to these terms and understand what they refer to, especially if they do not think they are looking for Ebola anymore and instead relate to VHF as a new and unrelated disease. That some of the volunteers reach the conclusion that VHF and Ebola are similar and, regardless, focus their attention on the signs and symptoms, can also suggest that the term used to describe the diseases may not be the most important factor in ensuring that the volunteers report the right cases. For example, one supervisor explain this as follows:

"It has related symptoms – the bleeding, fever… also continuous fever, vomiting… it was exactly what was said for Ebola. The signs and symptoms for Ebola are the same as VHF."

Despite not having interviewed the supervisors individually, it does seem like the supervisors remember the indicators and the signs and symptoms for them better than the community-based volunteers. This could be due to that they have more training, and also that they meet more regularly than the CBVs, as they meet weekly or bi-weekly with the branch, and then discuss CEBS.

Many of the volunteers can recall all the indicators, but some of these volunteers have not reported any cases yet and that they can recall them does not necessarily mean that they would accurately identify and report the right cases. At the same time, some of the volunteers who do not remember all the indicators and/or signs and symptoms have reported cases. We, at this time, do not know if these cases have been confirmed as actual cases, but this at least suggest that the volunteers are active and finding and reporting sick cases. That the data show this variety in understanding and remembering the indicators, does not enable us to conclude whether or not CEBS, as presently implemented, is working or not working, but it suggests that people understand things differently depending on their background, experience and context and that this should be discussed at each training to ensure that all the volunteers know what to look for. It also suggest that the terminology might be too complicated at the community level where people are not used to talking in

these terms, and that the focus should be on making the case definitions short and clear, so that the volunteers can relate to them.

Creating the case definitions together with representatives from the communities could be a way of ensuring that they are context specific. While the researcher was working with the CEBS program, the Sierra Leone Red Cross staff and volunteers were asked if they understood the case definitions. They all said yes. A reason for this can be the social desirability bias and that it is difficult for people to say that they do not understand something that has already been decided. Creating the definitions together with the community from the start might be a better approach than asking them to confirm or disconfirm their understanding after the definition has been created without their input.

The VSSs are supposed to be the filter that ensures that not all sick cases are reported to the CHO and DHMT as potential disasters or epidemics. This study also shows that the SMS works as a filter. Despite this, the VSSs are volunteers as well and should not respond to all sick cases. The indicators with case definitions are thus supposed to act as a filter as well, but for this to work, the CBVs need to know what the indicators and case definitions are. On the other hand, the volunteers might not use the indicators even if they can accurately recall them given their perceived need for reporting alternative and additional matters that they prioritize in their communities.

Red Cross volunteers are supposed to volunteer no more than 9 hours per week. This is a challenge with CEBS, as it is not time specific work, but requires the volunteers to be available for contact and reporting whenever something happens in the community that need to be assessed. One of the CBVs explain how he receive information from the community:

"Whenever I have time I walk around and search. If I pass by a house I talk like there is nothing. If there is a problem I will try to go in and ask if there is a problem, if there is an event. What is the cause and I will try to know. That is how I find things. I pass around and ask.I will not ask. I will just watch. If I see anything, I will try to go to the house privately, but I

will not personally introduce myself as if I am working for the RC because it frightens people. They will see it as Ebola is still around. I will just be passing and if there is any problem, I will ask."

The volunteers described receiving information from the community members in different ways. Some explained that they walk around in the community and ask people if there is anyone who is sick. Others said that they react to different things in the community, like if they see people sitting down and looking sick or being out in the sun to get rid of a fever. For the smaller communities, the volunteers said they would react if they did not see certain people that they would typically see in the community during the day. This quote imply that the volunteer is going around and asking in the community, but at the same time is saying that he does not ask so they understand he would report, but would just observe or go to the house privately, which does suggest that cases are still not reported actively from the community members and that the volunteers are not informing about CEBS and relying on the community members. This quote also support the previous findings discussed about fear of Ebola and suggests that the community was not informed about CEBS before it was implemented.

The CBVs were supposed to be contact persons in their communities if something happened or someone exhibited signs or symptoms of the 3 diseases. They are not, in other words, supposed to actively search for sick persons and cases. Sensitizing the community members about CEBS and what CEBS indicators and cases CEBS included was supposed to happen before the volunteers started reporting, as to encourage the community members to utilize the CBVs as contact persons for such matters. The CBVs are supposed to then report to the VSS if there is a case that matches any of the indicators. The VSS can assess over phone, but is expected to go to the community and assess together with the CHO if it cannot be done over the phone.

One of the supervisors explained his frustration about wanting to do a good job as a CEBS supervisor, but, at the same time, needing to do paid work and maintain his farm. Even if

many of the volunteers did not have paid jobs before CEBS, and are hence not prevented from working as such, they now find it difficult to look for jobs because they lack time:

"Most of us were not doing anything. Some left to work for RC, not because we were expecting money, but now looking at the whole process as a supervisor, there is no way for me - waiting for an alert 24 hours a day - cause that`s what we are told - 24hrs, we should be ready for alerts. How can I be engaged in something else? Let's say that I was engaged in organisation B and the volunteer called me and I was working somewhere else. How could I go there? I cannot. I don`t think CEBS would be very effective. So, we all choose to only stay with CEBS."

Challenges with combining farm work with volunteer work are also described by Dil et al. (2012), which can suggest that neither farm work nor CEBS is time specific work and that these responsibilities can hence be difficult to combine. This again suggests that information about CEBS and what is expected from the volunteers needs to be clearly communicated during recruitment, and that the volunteers need to be given the opportunity to evaluate, once fully informed, if they have the capacity to volunteer.

There are several potential reasons for why the volunteers are working more than anticipated when implementing CEBS. One of the reasons can be that neither the community members nor the volunteers understand that they should just report the 6 indicators- and why they should do that. One VSS in one of the FGD said something that clearly suggest the extended role the volunteers are having in some communities:

"The most important influence CEBS has had is that the volunteers almost act as health representatives in the community. By doing so, they report what happens and the community people come to them with their problems. For example when they have meetings with stakeholders and community members, people have problem with their drinking water..to maintain it..so these volunteers come in and come together and have now cleaned the dam, so they have clean drinking water. This has influenced the community a lot. They are keen to become RC volunteers because of the work the volunteers have done".

Another supervisor explained how they know what they should report, but the communities rely on them for being the link to help, so they help:

"..yeah, there are a lot of things we see around, like other community diseases which normally don't affect the general population, but just individuals. But it still does damage. For this, the volunteer still call us supervisors to ask what they can do because they rely on us that we are connected to some stakeholders, so we have to escalate the information to the relevant stakeholders. Like the two people that got missing. It`s not a part of our reporting, but the community got concerned and called the supervisor and the supervisor called ONS".

More focus on sensitizing the community about what they can and cannot expect from the volunteers and CEBS seems to be necessary, although it might be difficult to limit the reporting as long as the need in the community is so big. Another reason can be that the amount of time the volunteers are expected to respond within has not been communicated clearly to them, or that it is perhaps not even clear to the Red Cross staff how quickly the volunteers should respond and that this matter hence needs to be clarified for all.

The VSSs also have the option of performing assessments by phone. However, none of the VSSs included in this study mentioned doing this and suggested instead that they travel to the communities and assess, in person, the cases they receive alerts for. A reason for why they do this, can be that they are worried about submitting an inaccurate report or reporting something that is not a real case. This is something explained by the CBVs, who said that they always go and assess the case in person if they hear about something from the community members because they do not want to make a "wrong" report. They also explained that community members often report things that are not real. One CBV provided the example of a time that he was told that a person had died, but instead found the person alive when he went to assess. These are also often cases that do not match the indicators.

Another reason for responding to so many cases can be that the volunteers feel a responsibility for the community members or experience the community members as expecting more from than intended by the CEBS system due to a generally weak health

system and a need from the community to be supported with respect to more or other things than what CEBS is for. This again raises the question of if CEBS is feasible as an early warning system in places where there is need for other forms of support perceived by the community as more important, and if such other mattes need to be addressed prior or in addition to CEBS. To integrate CEBS into other Red Cross programs has been a focus, and it might be necessary for CEBS to be implemented together with other community health programs. One of the VSSs also explained how he would go and assess all the cases reported to him by the community-based volunteer to take the opportunity to give support and motivation:

"The volunteers are really ready to work because they even go the extra mile to top up their phone to report, and we, their supervisors, we make sure that whenever we get a call from a volunteer, there is a need for me to visit there, cause that will motivated the volunteer. When they see us there, it will motivate them. They will see that the supervisors are ready to work. We make sure we follow up. When we get a call, we go there and see what the situation is. Then we talk to them after and say; we are volunteers, keep it up, we are here to save our people from diseases. We explain to others that these volunteers are not on salary and that the supervisors are not either. We are here to help our community."

Some of the volunteers described alternative solutions to address the heavy workload. One volunteer explained that he had organized sub-groups of community member volunteers. These volunteers would be present in the local community where they lived and would look out for and report any sick people or deaths to him. By doing this, he avoided the need to go around everywhere all the time and felt confident that he would be told if there was anything to report. Another volunteer who was responsible for 5 communities in an area where the mobile network was poor said that he had an agreement with the community leaders that they would report to him if there were any sick cases or deaths, so that the volunteer would not have to travel around between the communities every day.

Although the volunteers made clear that it is difficult to combine CEBS volunteering with ordinary, paid work, they all also made clear that they want CEBS to continue and want to

continue volunteering. It seems clear from all the interviews and focus group discussions that the volunteers take a great pride in their volunteer work and the role they now have for the health of their people and nation. Many of the volunteers said that they choose to prioritize the volunteer work over ordinary work, although the reality might be that they, regardless of CEBS volunteering or not, lack paid work opportunities and potentially expect or hope for incentives.

One VSS explained the importance of CEBS and the reporting structure, the community-based volunteers; the hard and important work they were doing and how they deserved "motivation":

"They are eye witness. Us; the supervisors, the CHO, the DHMT, we are ear seeing it. Because the distances are so far, we are not in all the communities, but the volunteers are going out there, finding their way to find network, climbing trees to find network and report. They report all the deaths. We are the ones who give the information to DERC about death. Now that the SDB is over, they send swabbers. The communication chain for deaths to send swabbers is coming from us. Without us they would not know. Information are coming from the volunteers, to us, to CHO to DERC and to the swabbers."

When looking at the data analyzed in the previous sections, challenges with movement between communities, unclear information about monetary incentives and ID cards, and delay in promised in- kind incentives and sim card registration are challenges that are repeatedly mentioned. It is interesting and important to consider why these different delays and challenges, which obviously compromise the efficiency of CEBS, take place. This could be related to how the system is built up by the IFRC and Red Cross national societies, how they collaborate and how they organize procurement and logistics. Another reason could be delays from partners, as seems to be the case with respect to for the SIM cards, as the phone company does not manage to register the SIM cards. Independent of the reasons, this suggests that to implement a system like CEBS, it is not just the structure of CEBS itself that need to be in place, but also the structures of the support system that CEBS depends on. This indicates that CEBS either need more time for planning or an alternative manner of

ensuring logistics, to the greatest extent possible, when there is a need for a rapid implementation. It also suggests that, even when everything has been properly planned, there may be additional or external factors that cannot always be planned for or controlled, and which hence require that alternative solutions be promptly explored and implemented.

These logistical matters, together with the data about motivation, recruitment and experience of reporting methods and structure, demonstrate that external factors affect the program implementation and that flexibility is required of CEBS to be able to adapt to these factors and still benefit the community and achieve its purpose.

3.6 Collaboration and acceptance from the community

The volunteers are recruited from their communities by the paramount chiefs and community leaders because they live in the community and it is expected that they will see or be informed if there is a suspected case of viral hemorrhagic fever (VHF), acute watery diarrhea (AWD), measles, community death, flood or fire. It is also expected that they will report this to the Chiefdom Health Officer (CHO) for support in assessment, treatment and further reporting. Thus, it was interesting to discuss the collaboration between the volunteers and the community members, health care staff and stakeholders, as they all seem to play important roles for CEBS.

When the volunteers describe how they collaborate with the primary health units (PHUs) and the Chiefdom Health Officers (CHOs), they all say that they are working together and that the CHOs and PHUs appreciate their work. It is mostly the volunteer surveillance supervisors (VSSs) who work directly with the CHOs. Most of them said that the CHOs are available when they need them to assist with assessments, and that the CHOs are flexible and work hard for the community. The VSSs also explaind that the CHOs appreciate the support from the CEBS volunteers and work with them:

"The CHOs are really working with us, cause anytime we call on them, they will make themselves available for us. And even the nurse - whenever the CHO is not around, I will call on the nurse and she will be available."

One VSS also explain how important the CHO is to the:

"As we are trained on the signs and symptoms of illnesses- now this person is having fever and rash- can I prove that this person have Measles or Ebola? No. That is why we call the CHO, so they can come and confirm what is wrong with this person. The CHO will come and clarify, and then we will send the report. Whatever response you get from the CHO, that is what you report. The CHO will tell you that this person he will have to refer and then you will send in the report that there is an escalation".

Even if there were mostly positive comments about the CHOs, there were also discussions about jealousy and resistance, and the VSSs talked about how the CHOs were commenting negatively on the motorbikes the VSSs had because they themselves do not receive any means of transportation. The VSSs said that they, most of the time, bring the CHO on the motorbike when they go for assessments and this is mentioned most often as an important factor for the good collaboration. Many also say that the collaboration has improved after the CHOs and the District Surveillance Officers (DSOs) received phones and SIM cards registered in the same Closed User Group (CUG), as the volunteers could then call them and their DSO for free. The CHOs did not initially receive phones when the VSSs did. In all the FGDs among the VSSs, they spoke about how the CHOs were not happy about this and had complained that they did not receive the same as the VSSs. The CHOs have also, according to the research participants, asked the VSSs to borrow their motorbikes many times.

In one the FGD, the VSSs discussed how it can be difficult that the CHOs are jealous and that it can also be difficult to deny them when they ask to borrow the motorbikes, but they say they are clear in saying no- at least when the CHOs want to use the motorbikes for private use and outside the chiefdoms. This discussion suggests that, when implementing CEBS as a support for the existing health structure, there are challenges that can arise, with

potentially negative consequences. The CEBS volunteers come from an organization with more resources than the existing government and health system, and although they are volunteers who are dependent on the CHOs to assess the reported cases, diagnose and decide if they should report to the district health management team (DHMT), the CHOs become dependent on the volunteers for transportation and communications, which could disturb the existing roles and hierarchy. That the CHOs are also expected to respond with the VSS every time they report a case could also be challenging, as the CHOs have other work responsibilities. It does support the need for reporting more specifically and according to the decided indicators, to ensure that the CHOs are not overloaded with work and that the response efforts are sustainable. As the CHOs are there permanently while CEBS is supposed to fill a temporary gap, CEBS will potentially, at one point disappear together with the phones and motorbikes, potentially leaving the CHOs in a frustrating situation.

Although the VSS said that they always do the assessments with the CHOs, some of the CBVs said that the VSSs come alone when called and then call the CHO only if there is a serious case. There is only one CHO in each chiefdom, and with the challenging terrain that has been described and the high number of reports the volunteers make to their VSSs, it does not seem feasible that the CHO join the VSS for all the assessments. That the VSSs and the CBVs provided different information about this matter could also suggest that the VSSs come to support the CBVs for cases outside the indicators, even when they know that these are not cases that should be reported to the CHOs. As it has been described, the CBVs call the VSSs for advice on more than the 6 events they are supposed to report on, so this suggests that the VSSs function as the filter they are supposed to, but that the VSSs also believe that they are supposed to do all assessments with the CHOs and therefore reported that they do in the FGDs. Many of the CVBs who said that the VSSs always come with the CHO, have only reported 1 or 2 cases, and some have not reported any yet, so their answers seemed to be based more on what they are taught to do than what they have experienced.

When the VSSs were asked to give examples of collaboration with the CHOs, the VSSs offered examples of situations in which they have worked together with the CHOs:

"I have really been moving from chiefdom to chiefdom.I can remember coming from another chiefdom. Somebody was drowning in the river. For the CHO to move from where he was to where this happened, it was 7-8 miles. There was no fuel in my bike. The CHO got fuel and made sure that they got the swab collected from the corpse. So, actually people are embracing the project. They are using their own resources to see that things are happening.."

"There was a woman who was in a fire, and some part of her legs had been in the fire. The volunteer and me went to see her, and then I called my CHO and explained that the woman was severely burned and asked what to do. He said that he was in (name of another community), but if I could come and get him, he would come and see her. So, I went and drove far and took the boat and he travelled and we went back to the woman. So, they are really cooperating."

These examples show that the volunteers are called for incidents beyond the events they are supposed to report. It can be asked why the community members are not just calling the CHO directly instead of calling the CEBS volunteers first, especially as the CEBS volunteers do not have a health background. This supports the findings that suggest that the community members have high expectations of the volunteers, and also probably value and respect them, as according to the volunteers people accept and appreciate them more after seeing results of the CEBS work. As the CEBS volunteers are reporting on health indicators and advising people to go to health facility, it is likely that the community members do not know that the volunteers do not have a health background and are supposed to report the CHO, not diagnose or treat. This is also information that needs to be given to the community when informing about CEBS and what the community members can expect from CEBS.

Another reason for why they call the volunteers first could be that they are closer and easier to reach than the CHOs, and also that they know the VSSs have means of transportation. As demonstrated by the VSSs descriptions of how they work together with the CHOs, who also, at times, use the VSSs motorbikes, it is apparent that the VSSs and CHOs are dependent on each other. This can be positive and imply that CEBS is supporting the

existing health structure and vice versa, but, as discussed previously, it can also challenge the existing structure, create imbalance and foster dependency on the only temporarily available CEBS resources. In general, there was an increase in resources going into Sierra Leone and as associated with the Ebola response from the international community, which decreased when the outbreak slowed down. During the Ebola outbreak, an alert phone number was implemented: "The 117". Anyone could and should call this number if there were any deaths or suspected Ebola cases. During the outbreak, this alert phone was associated with resources and, according to the volunteers, calls made to this number were responded to by ambulances, including cases that did not match the case definition for Ebola. When the number of Ebola cases was decreasing and the emergency period was starting to phase out, the response from 117 also decreased and focused on death cases.

The volunteers expressed a lot of frustration about this. They explained that each district has an ambulance service, but that, to access it, the number for one person in the District Health Management Team (DHMT) has to be called and, if the individual(s) in need are not close to where the ambulance is, it takes hours for it to reach them. Some of the volunteers just laughed when asked if they can get an ambulance. In one of the FGDs, the VSSs started discussing whom they should call if they needed an ambulance, which illustrates that there is not a clear system in place for ambulance service and that this is not a service people are used to utilizing. The volunteers also explained that they would make hammocks and transport people who could not walk or use motorbikes, and they would sometimes use the VSS motorbikes. The volunteers expressed feelings of great responsibility for their communities, both because they are community members and because they are CEBS volunteers, and perhaps because they are both and thus have a link to accessing help for their community members, in the case that their reports warrant and receive response, which is not otherwise particularly available.

That the ambulance service is decreasing as the outbreak is decreasing, suggests that this was a service that was funded during and specifically for the outbreak, and that the existing health services do not have the necessary resources to keep this service running when the support for the outbreak disappears. This again suggests that the communities have noticed

and experienced the positive change in resources and response associated with international support, and thus turn to the Red Cross and CEBS program for support regarding health needs that extend beyond that which is intended of the program and expected of the volunteers. That the volunteers are from the community could make the community members trust them more, but it could also make it more difficult for the volunteers to set boundaries for the support they can give.

Some of the CBVs say that they are not talking directly to the CHOs or the PHUs, but that they report to the VSSs, who then communicate with the CHO and PHU. Some say that they will refer to the PHU and CHO if the VSS is not able to come to assess and has given the CBV permission to act on the VSS`s behalf. Other CBVs say that they work directly with the PHUs; they attend their meetings, go there and follow up with patients, ask if they can help and talk to the PHUs about how many people are seeking services. Many of the CBVs say that they never talked to the CHO in their community before the CEBS program, but that they now can and believe that the CHO is important for the community. As some of the CBVs said:

"The other advantage is that we can talk to our CHO. I think that is an advantage because before we didn't have easy access to them, but because they know now that we are working for CEBS, we can talk to them when we have a patient."

"Yeah, we work together, cause the CHO don't have time to reach all the villages or to have meetings with the communities, so they are happy. We tell the people to go to the health facilities, so they are seeing more people are coming there… instead of traditional healers... The people are now avoiding the traditional healers, the hospitals are now getting full because people are going there instead of traditional healers."

The data suggest that there are differences with respect to how the CBVs work with the CHOs, but do suggest that there is easier access to the CHOs and that they are communicating. The CBVs are also said that the CHOs do not have time to visit all the villages, and the CEBS volunteers can create a stronger link between the communities and

the CHOs, which can hopefully continue beyond CEBS. On the other hand, there should be community health workers (CHWs) from the MoHS present in most communities, and they should be the link from the community to the PHU and CHOs as well. As the volunteers are not necessarily people with health backgrounds, they are not supposed to diagnose or treat, but should refer persons who are ill or injured to health facilities. The medical assessment and diagnosis should be done by a Chiefdom Health Officer (CHO) or equivalent. The reports from the CEBS volunteers should provide an early warning about symptoms or events that could potentially be a threat. The volunteers cannot treat or diagnose people, so for them to be called instead of the CHWs, CHO or PHU staff is not necessarily positive.

This does suggest that the existing lines of reporting and the existing health service is not as available for the community as the community members desire, and that they see the Red Cross channels as more efficient by the VSS coming with the CHO, ambulance responding more to the Red Cross volunteer. This efficiency might be due to the CEBS volunteers having motorbikes to bring the CHO and phones with free line to call the CHO and districts surveillance office, and that they know the necessary contact numbers. As "117" is scaling down, there is no direct (or free) number for ambulance. One volunteer did describe how he told the community that he, through CEBS, had a phone to communicate out from the community and that this was what made them accept CEBS:

"I tell them that they gave us a phone and sim. Because the place where I am living, it is two miles away to communicate. They gave it to us to pass information."

The data reveal a need in the community for more support than epidemic and disaster surveillance. It is positive that the community members trust the volunteers and the Red Cross, and it is positive that this has led to more people seeking help and reaching health facilities. On the other hand, CEBS as an early warning system for epidemics and disasters can be less effective if the early warning reports are overwhelmed by reports on anything and everything else that, though perceived by the community as important, should not be reported to this system. The system, hence, might not have the intended effect of raising a warning alert when potentially real cases are reported. Although the data suggests that the

volunteers, community members, chiefs, leaders and PHU staff are all positive to CEBS and believe it encourages more people to go to the health facility, another negative consequence might be that, instead of supporting and strengthening the existing health structure, CEBS and Red Cross take over and, in the long run, make the existing structure weaker.

A few of the volunteers who participated in this study are CHWs. Many of the other volunteers said that there were CHWs in their community and that they were collaborating as they were doing the same job. Some of the volunteers said they did not have CHWs in their communities and some did not know.

As it is identified that the CEBS volunteers report more than they are trained to report through CEBS, it might be useful to identify where there are CHWs in the different chiefdoms and if they are not recruited as CEBS volunteers, the CHWs and the volunteers should meet and establish a shared understanding of their distinct, but potentially collaborative, roles in the community. When the CEBS volunteer is a CHW, the distinction between that which should and should not be reported to CEBS needs to be made clear.

One CBV who is also a CHW explained how he would report from his community. He gave different explanations and examples of what he would report to whom and what the PHU accepted that he reported and the VSS reported and seemed to be confused about the reporting structure. In the end, he concluded that he would report the serious cases directly to the PHU, as a CHW, and then report later to the VSS if these cases matched any of the CEBS case definitions. If the case was not, in his professional opinion, medically serious, but matched the case definition for any CEBS events, he would call the VSS first, as it should be the VSS, not him, who took such a case to the PHU. Using CHWs as CEBS volunteers is positive as they have a health background and a link to the PHUs, but it could also pose some challenges. With the CHW reporting both to the PHU as a CHW and to the VSS could lead to duplications of reports. It could also seem like, instead of using the existing structure of CHWs and PHUs, CEBS is creating an additional system for the CHW to report to, making the reporting more complicated and depriving the CHW of, to some extent, his or her role in the community. It does not seem efficient that the CHW should not be able to report directly

to the PHU when there is a sick case, but to go through the VSS, who is not necessarily a health worker.

In one of the communities, the nurses at the Primary Health Unit (PHU) expressed very positive attitudes towards CEBS and said that they saw more patients coming to the PHU after CEBS was implemented. As the nurses at the PHU often are from other parts of the country and do not belong to the community, they explained that they do not have a relationship to the community members and, hence, that the community members do not trust them enough to come to the PHU. They explained that the community members trust the CEBS volunteers because they are from their own community and would hence listen to them when advised to go to the PHUs. In another PHU in a different district, the CHO came over during the interview with a CBV and explained that he think the volunteers should be paid since they are doing so much work. When he was asked about his opinion of CEBS, he responded that it is an important support for them.

Most of the volunteers said that the community members are positive towards the CEBS volunteers, but when this topic was probed more during the interviews and FGDs, they explained that they did experience some challenges with the community members when they started reporting for CEBS and that there are still challenges in some communities when it comes to accepting the volunteers and reporting to them. For example, consider the following discussion that took place in one of the FGDs among CBVs, with respect to the topic of how the community responded:

"How was the response from the community to CEBS?"

"They were so happy with it."

"Well, actually some of them were afraid. But, later, after we sensitized them and they know we are their children and we are living with them, they were not afraid anymore."

"They were afraid because of Ebola. They will think there is still Ebola in the community. If you go there and ask for a sick person, they will refuse to respond to the question. But, since they know we are their children and living with them, they now have confidence".

These discussions entail an initial, immediate response that the community members are happy about CEBS, followed by, after some reflection, the suggestion that there is some resistance from the community and, in particular, as related to the fear of Ebola. The same pattern of response – initial expressions of favorable, positive collaborations followed by more nuanced discussions of challenges – arose when asked about collaboration with the PHU and CHOs. This thus suggests that the volunteers might believe that it is expected of them to be positive about CEBS as they know my affiliation to CEBS, because they believe the program is being assessed and thus should be positive or because of social desirability bias and the volunteers want to show that they are doing well and the program is running well. It can also just be an automatic response, a reflection of a potential desire to respond quickly to the questions asked, and offer a polite or positive remark prior to reflecting and discussing more critically, as this might be the custom in the Sierra Leone culture and context.

One of the reasons for this fear among the community members could be the lack of knowledge about the Ebola virus among the community members, and also in the world in general. Another reason could be the many different rumors about what Ebola was, where it came from and what happened in the Ebola treatment centers (ETCs). This, together with a high mortality rate at the ETCs and hospitals, and the reality that many people never returned to the community after being admitted, led to fear in the population. Some of the volunteers explained that more people would stay at home or go to traditional healers when they were sick during Ebola, but also before Ebola, and CEBS had changed this:

"…difficult to go to hospital and people don't go until they are advised. Before, people said no to going to the hospital. They stayed home with native medicine. This changed with CEBS".

"Before, they didn't listen and they would just lay down in their house and drink this native medicine. After the program was implemented, people have started to know now, this hospital issue is very much good for them".

These quotes suggest that the behavior in the community has indeed changed with CEBS and as people understand that it is safe to go to health facilities and that it helps. That the outbreak was declared over also influenced the response from the community members.

"*They were afraid yeah, since we were told to report any matter related to Ebola, if they were sick, they would hide it from us. But as they have cleared Sierra Leone free from Ebola, they are more open-minded to us."*

What is clear from this study's data is that, when the CEBS volunteers started to work in their communities, they experienced resistance from the community. They also experienced anger directed towards them. When asked why they thought that people were angry with them, they responded that people accused them of bringing Ebola back, for working for foreigners and being out to kill them, and for making money off Ebola. Talking about Ebola in the community was very sensitive and difficult because most of the people in the country have had difficult and even traumatic experiences with Ebola. The volunteers explained that many people have been sick themselves, they have lost their loved ones and they have been under strict regulations for how to live for over a year. People in areas with positive Ebola cases or who had been in contact with positive Ebola cases were quarantined for 21 days to prevent transmission, and could then not move outside their homes and go to their jobs or farms. There were also, at times, delays in the delivery of food and water to the quarantined areas (Oxfam, 2015). Many people have lost their jobs and many farmers lost their crops because of the Ebola outbreak. They were therefore angry when the volunteers came, both because they were asking for information that people were afraid to give out and because they thought that the Red Cross paid the volunteers to do this work and were upset that someone would make money from something they lost their income over. One CBV talked about this in the FGD:

"Like, anytime we go there, people are thinking that they (the Red Cross) are giving us money. They say that they are paying us to kill them."

In these situations, the volunteers said that they tried to explain more about CEBS to the community members. They said that they have spent a lot of time sensitizing the communities and explaining what CEBS is for and why it is important, and that people are listening and accepting the more now, but they said that it is difficult to get people to come when they call for meetings to inform about CEBS. One CBV explained:

"Normally, it was so difficult to assemble people to come. You know in Africa, poverty is a big problem, so if you are going to have someone come and stay with you for two hours or three hours, they are expecting something. The first call, they will have to accept it, but if they don't get anything, they will not come back. Maybe 100 comes for the first meeting, then 20 will come for the next meeting".

When the CBVs were asked to discuss, in one FGD, if there was anything they thought they could do to make people come to their meetings, one of the volunteers explained that they could only give encouragement.

"It is really not easy, because we have nothing to give them, until we talk to them. Talk and talk. The only thing we have to give them is encouragement. That's all we have to give to those people, so they will understand. Encouragement, encouragement, but we will not give them anything else, so it's just about encouragement."

The volunteer looked and sounded frustrated when describing this, and it was obvious that he not think that encouragement was enough to give to people. It came up in several interviews and discussions that the volunteers wanted to have something to give to the people who come to the meetings. They said that they do not want much, just some refreshments. Several of the volunteers say that people would come the first time they called for a meeting, but when they see that they do not get anything, they will not come for

the next meeting. Some people also get angry that they volunteers call them away from their farm work without giving them anything.

Many of the volunteers wanted more support from the supervisors and the Red Cross branch to inform and sensitize the communities, both when introducing CEBS and after they had worked for a while and community members were asking questions. Most of the volunteers said that the Red Cross had been there and talked to the stakeholders, but that it was the stakeholders (the community leaders) who gathered the community for information meetings. Who leads these meetings varies. In some places it was the community leaders and in some places it was the volunteers. Some of the volunteers said that representatives from the health facilities had participated in some of the meetings. Despite this, not all community members had participated in the meetings and not everyone had understood, so there were a lot of questions for the volunteers, and they explained that they found some of the questions difficult to answer alone. This suggests that communication and information is important, both for the volunteers from the Red Cross staff and also for the community members. The data suggest that not all the volunteers feel confident enough to inform the communities about CEBS on their own and would appreciate more support regarding this. One volunteer explained that the BHO had informed the community about CEBS via the local radio, which he thought was a good approach that should be used more.

Most of the critique that the study participants described receiving from the communities was about making money and bringing Ebola back or taking people away. This was brought up particularly often in one district and not so much in the other two. The truth was, of course, that they were not making any money and that they were working as volunteers for their communities. For the 2 communities trained on more indicators then Ebola, they could also show that they were not just looking for Ebola, but for other diseases and events as well, and that they were doing this because they did not want any other diseases to create an outbreak like the Ebola outbreak again. They perceived this as gradually enabling them to gain trust in the communities and, although people were afraid of Ebola, they did not want the outbreak to increase or return, and they did not want any other diseases to

come and spread either. This fear and reluctance associated with Ebola, could also be a reason for why the district that was only trained on Ebola quickly started to report more things. The volunteers who participated in this study suggested that, if they supported the communities with what they felt they needed support for, the communities would more likely accept them.

The response from the communities, as described by the participants, also seemed to be influenced by the size of the community and the relationship the volunteer had with the community members. As said before, some volunteers found it difficult to get people to come for meetings, while others had weekly meetings in their community, in which they would always talk about CEBS. Some even sat together with the whole community every night. Some of the volunteers talked about the increased respect they have gained in the community, both from the community members and the stakeholders, and explained that they are requested at the community meetings to talk about CEBS, while others talked about how the community members would mock them for working for CEBS and making money off of it.

The supervisors also laughed when explaining that, normally, the leaders were the ones who updated the community members about incidents and happenings in the community, but that now it was the CEBS volunteers who updated them. The supervisors seemed proud of this. When asked how the leaders responded to this whether this could potentially disturb the existing structure and hierarchy in the community, they answered that the community leaders were positive, and the volunteers always reported to the leaders as soon as they hear about something happening. For most of the communities the researcher went to during the data collection, the community leaders were seen first to tell them about the study and ask for permission to interview the CEBS volunteers. For some of the communities, the researcher went together with the volunteers and got the impression that the community leaders were positive to the CEBS volunteers. That the volunteers were informing the community leaders first about what was going on and that the community leaders were the ones who recruited the volunteers might influence the way the leaders accept this role of the volunteers.

The volunteers' affiliation to the communities is important for the acceptance from the community; that they are from the communities, know the community members and have their families in the communities came out as the most important factor to why the community members were listening to them, trusting them, giving them information and following their advice, and many of the volunteers say that the community members would not have accepted them or listened to them if they would have come from somewhere else.

The volunteers refer to themselves with family member role to the community members. One of the CBV explained how they are brothers and sisters of the community members while another CBV says they are the children of the community. This difference could have been related to the age, but the volunteers who called them children, was not one of the youngest participants. They could be referring to the community leaders as the respect the community show to the community leaders could be similar to one of father who takes care of his children, being the community members, and the community leader is the one who decide what should happen in the community.

The collaboration between the VSSs across the chiefdoms came up in several of the FGDs as a positive consequence of CEBS. The volunteers said that they feel safer, as they can now get help from other volunteers in bordering chiefdoms who might be closer to them than other volunteers and able to help in their own chiefdom.

"One example is that there was someone in the chiefdom next to me, where I am not responsible, but some volunteers came to me and asked to help with someone who was drowning and I went to do what I could to help."

Interestingly, the study participants describe two very different responses from the community towards them, with respect to their roles as Red Cross volunteers. Some people trusted them more because they knew of the Red Cross and other projects that the Red Cross had carried out in the community, and they hence trusted the organization. Others,

however, were afraid of the volunteers because they did not know of the Red Cross before the Ebola outbreak and only associated the Red Cross with safe and dignified burials (SDB).

Since dead bodies were highly infectious, SDB was implemented, so instead of the family members cleaning and burying the bodies, an SDB team would come and conduct the burials. The Red Cross was the primary contributors to SDB teams and they were working all over the country to respond to dead bodies and conduct burials. Many communities had never seen a Red Cross vehicle, worker or volunteer before or after SDB and were therefore scared when the CEBS volunteers came in Red Cross t-shirts. This was especially in the areas where CEBS was implemented when the Ebola outbreak was over. The community members thought this meant that Ebola was back.

From all the volunteers, it seems like the attitude and acceptance from the community members has improved over time. Some explained that there are a few people still in the community who are reluctant to accept CEBS, but most explained that most members of the communities are very happy to have CEBS and are appreciative. Many of the volunteers said that they are receiving feedback from the community members that they are grateful for the work they are doing and for watching out for the community.

Some of the volunteers say that they think the attitude in the communities has changed because they have seen the result of CEBS. They have seen that CEBS helps and feel safe because of it:

"I think community people are appreciating it so much. Knowing that they have people around them who protect them and look out for them, they feel safe."

The different data collected from the volunteers suggest that the understanding and knowledge about CEBS has increased among the community members. This, it seems, is due to sensitization and information given, both by the Red Cross and other partners. Some of the volunteers had worked for other partners and with social mobilization and thus were familiar with health messages about Ebola. The data also suggests that the community was

influenced by initiatives from other partners, which emphasizes the need to identify other initiatives and collaborate with partners to avoid duplication, and to be able to complement each other.

The data also suggest that some of the volunteers found the negative feedback from the communities in the beginning to be difficult. Although most of the volunteers express pride when they talk about their volunteer work and their contribution to the community, some also describe being excluded from their community in the beginning of their work. This emphasizes the importance of supporting the volunteers, both in terms of making them confident about CEBS and informing the community about what they are responsible for and what should be expected of them. It also suggests that it is important to follow up with the volunteers regularly and have a system for identifying and talking about challenging and difficult incidents that the volunteers experience in the communities.

As already described, it is obvious that the volunteers have a sense of responsibility for the community members, both because they are CEBS volunteers and because they are members of the communities. Because they are members of the communities and have relationships to the other community members, it is difficult to not use the link they feel they have through CEBS to generate response to health issues. Although people can go to the health facilities by themselves and get help if they are sick, the data suggest that many people do not go until they are advised to do so by the CEBS volunteers.

There can be different reasons for this, with one being that people are not aware that they can go to the health facility. Since many volunteers have talked about the lack of knowledge about diseases in the community, another reason can be that people do not know when it is necessary to go to the health facility. Difficult access can also be a reason, as many of the volunteers explained that the distances are long and that some communities cannot be reached by motor vehicles. Some of the volunteers also said that the PHUs lacked medicine and equipment, and that people did not always see the point of going there, as they were not sure there would be medicine to treat them. The nurses at the PHU who were consulted with during the fieldwork period also said that they lack medicine and equipment. By

reaching out to the CEBS volunteers, community members can potentially receive more support, either in the form of help carrying ill or injured persons to the health facilities, motorbike transportation, or links to the ambulance. With the fear generated by the Ebola outbreak, people have been more reluctant to go to the health facilities, which the data suggests is the main reason for not seeking help. Since the CEBS volunteers belong to the communities, it might feel safer to go through them than directly to the health facilities. This is supported by the information from the PHU staff, who said that more people are coming to them and seeking health services because they trust the CEBS volunteers who advise them to do so.

Because the volunteers are advising people to go to the health facilities, some people have expected the volunteers to pay the fee at the health facility. Like one of the CBV said in one of the interviews:

"*There are still some challenges actually, because when we are working, sometimes people point fingers at you and they are afraid of us and if you go here and ask for a sick person, they will ask you: " Are you going to be responsible for the money for the hospital"?"*

One of the CBVs also feels a responsibility to address the issue of payment at the PHU and show frustration over the issue:

"..yes, we are asking the supervisors to talk to the people at the health center. We are referring to PHU, but the amount they are asking from the community people is too high. We need intervention. I don`t know if we can talk to DHMT or someone, so that they can minimize and we can assist the people to get treatment. They have to pay 20 000. The get angry and ask why we are referring when they have to pay. This makes them hide sick cases again…"

This quote also support the impression of the trust the volunteers have in CEBS and how much they believe CEBS can accomplish.

Some of the volunteers find it difficult that people ask for money for the PHUs, while others said that they just tell the people that they are volunteers and do not have money and the people accept that. Some also explained that the PHU staff will sometimes ask for less money from the patients if they come with a CEBS volunteer. Some of the volunteers said that the patients are taken more serious if they come with a CEBS volunteer. A couple of the volunteers said that people should help each other, and that included giving money if they had some. He said that he would give a little bit to help if he could, and he therefore thought that the volunteers should receive some money to have in their pockets for when it was needed.

In general, the analyzed data suggest that there have been challenges for the CEBS volunteers with respect to being accepted by the community members. This seems to have improved over time because of sensitizing and information given to the community and because they have seen the results of CEBS and how it is supporting both the PHUs and the communities. That the volunteers are from the communities and are known by the other community members is said by all the volunteers to also be an important factor. The volunteers are saying that they and the community members have increased knowledge after CEBS and behavior has changed in the community:

"People are now aware that a problem for mister A is not a problem for mister A alone, but a problem for the whole community".

As most of the resistance from the communities is perceived and explained by the volunteers with respect to the fear associated with Ebola and the consequences Ebola has had on the society and the individuals, it would have been interesting to compare this to the ways in which a community might respond to community-based surveillance (CBS) in a situation in which it is not implemented at the end of a big outbreak, but before. It would also be interesting to see if the type of outbreak influences the attitudes in the community. The Ebola outbreak was dramatic and involved a disease that there was little knowledge about, that was not preventable by vaccine or curable by treatment, and that spread quickly and had a high mortality rate. This can suggest that the response from the community

members would have been different if the outbreak was different. It does not appear that the literature published about CBS contains any studies that would enable such a comparison now.

CHAPTER 4- CONCLUSION

4.1 Summary of study

This study has explored the CEBS volunteers' perceptions of CEBS as a system and the influence and impact it has had on the community. The study shows that the volunteers are motivated to volunteer by a desire to want to help their community, seeing results and also expecting or hoping for incentives in some form. The volunteers believe CEBS has had a positive impact on the communities, that it prevents Ebola and other diseases and that it has decreased the mortality rate by providing a direct link to the health facilities, advising people to use the health facilities, learning about new diseases and teaching this to the community members so that, ultimately, more sick people are detected early.

The reluctance on the part of the community to welcome the CEBS initiative due to fear of Ebola has been a factor that has made the reporting challenging for the volunteers, and also demonstrates that the Ebola outbreak established not only an urgent need for such a system, but also made the context and circumstances in which the system was implemented unique. Community sensitization and the recruitment of volunteers from the community, together with what are perceived as visible results of CESB, has increased the level of community acceptance and participation.

The increased participation has led to CEBS reporting beyond the planned indicators, which has proved the system to be flexible and provided additional support to the communities beyond the disaster and suspected epidemic-prone disease reports the system was intended to accomplish. But, at the same time, this has also increased the workload for the volunteers, adding additional challenges and potentially compromised the efficacy of the CEBS system as surveillance system and timely warning for epidemic-prone diseases and disasters

Most of the volunteers find the coded SMS to constitute an easier method of reporting than written forms, and they also believe that it is much faster and easier to call and send SMSs if and when there is sufficient mobile network, which is one of the main challenges with CEBS in Sierra Leone. The other main challenges identified by the volunteers were unregistered SIM cards and far distances and lack of transportation. Although these are concrete logistical challenges, this study suggests that there several systematic challenges lead to and compound the logistical challenges. High expectations from the community and unclear expectations from the Red Cross regarding the roles and responsibilities of the volunteers, together with unclear criteria for volunteer recruitment, for example, seem to contribute to the challenges the volunteers experience and describe.

A consideration of the volunteers' perceptions of and perspectives on CEBS, and learning about their experiences with the program, also raises several questions about the indicators. Are they adapted to the context? Do the volunteers understand them? Are they relevant to the context and are they priorities for the communities? What is the ideal number of indicators with respect to feasibility and efficiency? Are fewer indicators more likely to be remembered and might fewer indicators ensure that only these indicators are reported? Is the reporting influenced by the situation and need in the communities only or can more trainings, sensitization and clear communication about expectations and roles lead to a more specific system? Is it right and possible to implement CEBS for specific diseases when there is a need for so much more? The structure of the relevant factors around the system itself and how this influences the results has also been discussed in this study.

This study has reported some important perceptions from the volunteers and identified areas that need to be considered when implementing CEBS, as well as matters that could benefit from further consideration.

4.2 Recommendations

This study has presented the volunteers' perception of CEBS, both regarding positive aspects of CEBS and challenges. Through the interviews and focus group discussions (FGDs), areas that can be improved have been identified and discussed and some recommendations for future implementations have emerged from the analysis of the data. Though every context is unique and different, and though there are both external and internal factors that make it difficult to suggest a universal "recipe", some recommendations are as follows:

- More involvement from the Red Cross and clear criteria should be strived when recruiting volunteers. Many countries have CHWs and if and how to integrate them into CBS, as well as how to avoid duplicating or compromising roles is warranted.
- Recruitment of already registered Red Cross volunteers should be prioritized when possible. If not possible, volunteers should be registered as Red Cross volunteers and provided with the standard introductory training as soon as possible.
- Clear communication about expectations between Red Cross staff, volunteers and communities should be ensured and increased sensitisation of the communities pursued.
- Discussions should take place with community leaders before deciding what CBS should be implemented for and to ensure that it meets the needs of the communities.
- Discuss, together with relevant community members what to call the indicators instead of asking if the indicators are understandable only after they have been selected.
- Provide regular refresher trainings with practical exercises on identifying cases and reporting by mobile phone, placing calls and sending the SMS.
- Have a monitoring plan, and start monitoring and follow-up directly after the implementation.

- Plan for alternative logistic solutions, especially for mobile phones, network, CUG and credit top-up.
- Where volunteers have their private phone, these can be registered and given top-up instead of giving new phones and sim, to save cost and logistic challenges.
- Have an alternative way of reporting for areas without mobile network planned before implementation.
- Reimburse expenses related to CEBS.
- Provide alternative solutions for transportation so that the need for reimbursement decreases – for example, bicycles.

4.3 The relevance and contribution of this study for the field of community-based surveillance and mHealth

As found through the literature review, there is limited research about community-based surveillance, and particularly with respect to the volunteers' experiences and perceptions. As the volunteers are the main users of CEBS, the ones who collaborate with the community and the existing health structure and indeed the ones that the entire system depends upon, their perspectives and perceptions contribute important knowledge about the CEBS structure, the user-friendliness, its adaption to the local context and acceptance from the community and existing health and surveillance structures. This study has produced important knowledge about the complexity of community-based surveillance (CBS), and it has identified areas that should be considered when implementing CBS, both for event-based and disease case definition- based systems. This includes the surveillance program logistics, the volunteer structure, including recruitment, expectations and follow-up, and the content of and methods for training. The importance of being clear about expectations, at the level of the organization, the volunteers and the community, has emerged as particularly important. The volunteers who participated in this study have found CEBS to be important for the community beyond the objective CEBS was intended for. This demonstrates the flexibility of CEBS, but it also suggests that the needs in and as perceived and prioritized by the community can be different than those of CEBS and can influence

how CEBS is perceived and used, hence resulting in discrepancies in how the volunteers versus the Red Cross conceive of their roles and responsibilities and implement the system.

This study has provided valuable insight into how CEBS is actually working "on the ground", from the perspective of the volunteers themselves, including how they, as both volunteers and beneficiaries perceive and experience CEBS. The findings in this study surround fundamental issues with community acceptance, structure of volunteers and technicalities with the surveillance system, which is believed to be relevant for all context and the findings in this study is thus seen to be transferable and useful for implementation of CBS in other contexts.

4.4 Study strengths and limitations

There are both strengths and limitations with using a qualitative design and methodological approach, and interviews and focus groups discussion (FGD) as data collection methods. This methodological approach was rationalized, and has indeed served its purpose, as one that prioritizes and enables an exploration of the volunteer's perceptions, experiences and perspectives, and as an approach that fosters in-depth understanding. With a quantitative approach or survey, data could have been collected from a larger number of volunteers, but it would not have been as detailed, and such an approach would not have provided opportunities for probing, asking follow-up questions or exploring nuances, complexities or unexpected and emergent themes.

Focus group discussions (FGDs) can provide a more comfortable and less intimidating means of research participation than individual interviews, and people who do not initially believe they have anything to contribute may find themselves engaged and encouraged by the group and the discussion. At the same time, FGD participants may not be equally engaged, despite the facilitator's best efforts to encourage this, and the data produced in FGDs does risk representing that which is socially acceptable more so than that which is true, if and when participants are uncomfortable sharing their honest opinions (Kitzinger, 1995).

In this study, I found that the volunteers, in general, discussed challenges more extensively and thoroughly in the FGDs and that the FGD seem to create an arena where they felt comfortable discussing their experienced challenges.

In-depth interviews, as well, have both strengths and limitations (Boyce et al, 2006). One limitation is that persons invested in a particular program may want to show that the program is working and can thus be biased in their responses. This is something that I believe occurred at certain points in this study when, for example, the volunteers at least initially responded to certain questions by saying that everything was good. As the conversations evolved and they continued talking, their descriptions became more nuanced and they began discussing challenges as well. Hence, in the same ways that the in-depth interviews were associated with this potential limitation, they also enabled it to be overcome, to the extent that follow-up questions and probes could be used to encourage the participants to freely discuss their experiences, both positive and negative, in detail.

Another limitation is that the findings from qualitative studies that utilize purposive sampling and include a limited number of participants cannot be generalized or claimed to be representative in any absolute sense. However, the strength of this research is that, by not striving for generalizability and representation in this manner, subjective experiences and perspectives can be explored in detail and in-depth. Moreover, the study sample included volunteers from 14 different chiefdoms and a variety of communities, and a considerable degree of variation was achieved. This suggests that the collected data does likely, to some degree, reflect and account for at least many of the significant differences present among the population of CEBS volunteers and in the different contexts and areas in which they are working. On the other hand, the inclusion criteria deliberately excluded volunteers working in areas that were not accessible by motor vehicle, and this is an obvious limitation with potential implications for the data collected, as there could indeed be differences in the perceptions and experiences of the volunteers living in areas that are not accessible by motor vehicle and those who are. The volunteers living in more hard-to-reach areas are likely to have more logistical challenges; less frequent contact with their

supervisors, and depending on mobile network, could have more challenges with giving alerts and reports. If they are responsible for several communities, moving between these communities may be more challenging. Participating in meetings with the other volunteers is also likely to be more challenging. Despite this, I believe that this study provide valuable information and knowledge about the challenges and positive aspects of CEBS in Sierra Leone, as experienced, understood and described by the volunteers. By using triangulation and seeing the similarities in the information from interviews, FGDs and informal conversations, I believe strengthen the confidence of having collected data that can reflect the perception of the CEBS volunteers in Sierra Leone.

Given the qualitative research design, it was also not within the scope of this study to determine or assess the effect of CEBS with respect to the number of cases detected and whether or not this system detected more cases than the regular surveillance system, but it does provide valuable insight into the volunteers' perception of the system's impact and efficacy. It also gives an understanding of the communities' perceptions of the program, as experienced by the volunteers who participated in this study, and of the ways in which this affected these volunteers and how they conceived of and performed their duties.

My dual role as both a Red Cross delegate working with CEBS program and a researcher can be associated with both limitations and strengths, as I have already discussed in the methodology chapter's section about reflexivity. My knowledge about CEBS and the implementation in Sierra Leone could create bias with respect to how I analysed the data. That some of the volunteers knew my role with CEBS could also influence their answers. I explained my role clearly to the volunteers and, by doing so, feel confident that I minimized the potentially negative influence of my dual role. I also feel confident that my role as a Red Cross delegate has not introduced an unproductive form of bias to the study and that I have achieved a transparent account of such matters. For example, at various points in the discussion and when offering analyses and interpretations of the findings, I have drawn upon my experiences from working with the program and familiarity with the context in which these volunteers are working, but I have been clear about where and how I have done so and have clearly and directly explained this in relation to the empirical material

and findings. I strongly believe that my affiliation and experience with CEBS has added value to the study and enabled a deeper understanding of the volunteers' experiences, perceptions, perspectives and the context in which these are implicated.

CEBS was recently implemented in Sierra Leone and the volunteers have limited experience, which influenced, at times, their responses. Some of the participants, for example and as mentioned, have never reported a case, which makes it difficult for them to respond to questions about case reporting and response, and particularly those questions that asked them to describe their own experiences with such. On the other hand, doing a study at such an early stage provides useful information about the preparation for and implementation of CEBS, based on what the volunteers know and experience now and without being influenced by other factors that might arise as the program moves on.

4.5 Implications for further studies

As just described, this study was conducted during an early stage of the program. This is also the case with most of the other studies that have been published about community surveillance, many of which have been pilot studies. Thus, it is important that studies are conducted for CBS/CEBS programs that have been sustained over longer periods of time. It is indeed necessary to evaluate if CBS is sustainable for longer periods and to also assess the effectiveness of using event indicators as opposed to or in combination with disease case definition indicators, and to enquire into which kinds of areas and circumstances one approach versus another is more relevant and effective.

It would also be interesting to explore volunteer perceptions of the system after they have volunteered for a longer time, in a situation in which the system has been sustained and potential challenges have been more thoroughly addressed, to see if they have different perceptions and perspectives with respect to the challenges encountered, usefulness and effect on the community, as well as what their thoughts are about particular topics of interest, such as incentives.

A quantitative study to research the effectiveness of CEBS, the number of true cases detected by CEBS and if CEBS is detecting cases that would not have been detected by the regular surveillance system, is necessary to evaluate if CBS is an effective surveillance initiative.

The Ebola outbreak constituted a complex and unique situation that dramatically impacted the nation and its entire population. This study suggests that the nature of the outbreak influenced the ways in which this CEBS program was received by the communities, in manners that were both positive and potentially challenging for the volunteers. Thus, it would be interesting to compare the findings from this study to those of one conducted in a different context and under different circumstances, particularly with respect to matters of community collaboration and acceptance.

APPENDIX

1. INTERVIEW GUIDE
2. GUIDING QUESTIONS FOR FOCUS GROUP DISCUSSION
3. CONSENT FORM
4. RESPONSE FROM REK
5. ETHICAL APPROVAL FROM NSD
6. ETHICAL APPROVAL FROM OFFICE OF SIERRA LEONE ETHICS AND SCIENTIFIC REVIEW COMMITTEE

Appendix 1

Community Event-Based Surveillance

INTERVIEW GUIDE

This flexible, semi-structured interview guide aims to facilitate an in-depth discussion and understanding of volunteer experiences with and perspectives on the community-based disease surveillance and monitoring system, perceptions of its strengths and weaknesses, and the challenges potentially encountered while working with it. The interview guide is organized in accordance with relevant themes, including a number of open-ended questions and possibilities for probes.

Background

- Name:
- Phone number:
- Gender:
- Age:
- Educational/professional background:
- Amount of time working as a Red Cross volunteer:
- Chiefdom of volunteering:
- District of volunteering:

The implementation process

1. How were you recruited and how long before the training did the recruitment take place?
2. What motivated you to volunteer with the Red Cross and this project?
3. Can you tell me about the training? What did it involve? What did you like about it? What did you dislike about it? Was something missing?
4. What is your understanding of what CEBS is and why CEBS is needed?
5. How prepared did you feel when the time came for you to start reporting?

6. Were there any challenges during recruitment, training and preparation for starting to report? Please explain.
7. How was the community informed about you and CEBS and how did they respond to you as a CEBS volunteer?

The reporting process

8. Can you tell me how you identify cases/events in your community that need to be reported? Do you think you are made aware of all cases that should be reported?
9. Can you describe the reporting system/flow for CEBS and how you are reporting?
10. Can you tell me what you report through CEBS and why you report this?
11. Can you tell me about the response when you report? Who respond and how?
12. How is the collaboration with the health facilities?
13. Do you know why you are reporting both by phone call and SMS? Are there any challenges with this?
14. Can you describe how you think this way of reporting is working? What is working well and what is challenging?

The function of the system itself

15. Can you describe what effect you believe CEBS has on the community and what the results from CEBS are?
16. Can you describe any challenges you have experienced while volunteering for the CEBS project?
17. Can you say something about the support and follow up you are receiving? What is good and what could be improved?
18. How does it affect you to respond to the sick and dead cases? Do you get support from this? Is there a different support you need?
19. Was there any existing ways of detecting diseases and disasters in the community before CEBS? If so, how is CEBS affecting this?

20. Do you have any suggestions to how CEBS could be improved in any way? For example in regards to understanding and using it, efficiency, relevance?

21. Is there anything else you would like to say about the CEBS system?

Probes:

- Would you give me an example?
- Can you elaborate on that?
- Would you explain that further?
- I'm not sure I understand what you're saying. Can you explain it further?/Is _____ correct?
- Is there anything else?

Appendix 2

Guiding questions for focus group discussion on Community Event- based surveillance system

ENGAGEMENT QUESTION:

1. What is Community Event- Based Surveillance (CEBS)?

EXPLORATION QUESTIONS:

2. How were you recruited to be a CEBS supervisor/community volunteer?
3. How were you prepared to use CEBS? Were you enough prepared?
4. How do you follow up alerts from the community/from the volunteers? What are the challenges for following up and what are the support and resources you have for following up?
5. Do you know why you do both phone calls and send sms? Is there any challenges in reporting like this?
6. How relevant for your community is the case indicators you report on?
7. How is the acceptance from your community? How do you work with the community/community members?
8. What kind of response is activated when you report a case?
9. How is the collaboration with CHO/PHU/DHMT? How can this collaboration be improved?
10. What are the positive aspects of CEBS?
11. What are the challenges with CEBS?
12. How could the implementation of CEBS and training have been better?
13. What can make the CEBS system more relevant?more efficient?better to work with?
14. How is CEBS integrated into other RC programs/Activities?

EXIT QUESTIONS:

15. Is there anything else you would like to say/discuss about CEBS?

Appendix 3

Request for participation in a research project

"Improving Disease Surveillance in Sierra Leone: A Qualitative Study of Volunteer Experiences with a Mobile Community Event- Based Surveillance System"

Background and purpose

This is a request for you to participate in a research study that intends to explore your experiences with and perspectives on the community event-based surveillance system. This study is motivated by the need to evaluate the system thus far, adapt it to better meet the needs of the volunteers who work with it and the communities it serves, and improve it as necessary prior to implementing it in other countries. As a volunteer working with this system, your perspectives and experiences are highly valued by the Red Cross. You are thus being invited to discuss your experiences with and perspectives on the system and its implementation, your perceptions of its strengths and weaknesses, and any challenges that you have potentially encountered while working with it.

This study is being conducted in connection with the researcher's master's project at the University of Oslo, Norway and in cooperation with the Norwegian Red Cross, the Sierra Leone Red Cross Society and the International Federation of Red Cross and Red Crescent Societies. The project is funded by the Norwegian Red Cross.

What does the study entail?

The study will involve individual interviews and focus group discussions. Focus group discussions will take place among 8 participants each. You are being invited to participate in either one individual interview or one focus group discussion. Both the interviews and focus group discussions will involve discussion of volunteer experiences with and perspectives on the system and its implementation, perceptions of its strengths and weaknesses, and potential challenges encountered while working with it.

The researcher will conduct the interviews. The researcher will facilitate the focus group discussions. Two locally hired staff will also observe the discussion. The interviews and focus group discussions will, with the permission of the participants, be audio recorded for later transcription and analysis. Time and place for the interviews and focus group discussions will be agreed upon between the researcher and participants. Refreshment, meal and a gift of gratitude will be provided for all participants.

Potential advantages and disadvantages

Study participation will entail discussion only and no discomfort or disadvantages are expected. The information that you provide will have no negative consequences for you or other volunteers, the Red Cross and Red Crescent Society or your local community. With the information that you and other participating volunteers provide, efforts will be made to improve the implementation and structure of the community-based surveillance system in a manner that better meets the needs of the communities and volunteers.

What will happen to the information about you?

The data that are registered about you will only be used in accordance with the purpose of the study as described above. All the data will be processed without name, ID number or other directly recognisable type of information.

All data will be fully anonymized upon project completion in June 2016. The University of Oslo, the International Federation of Red Cross and Red Crescent Societies, the Sierra Leone Red Cross Society and the Norwegian Red Cross will have access to the fully anonymized data. If you agree to participate in the study, you thus also consent to the release of the anonymous data to the University of Oslo, the International Federation of Red Cross and Red Crescent Societies, the Sierra Leone Red Cross Society and the Norwegian Red Cross.

Project findings will be published in the form of a master's thesis and/or articles. These will be shared with the national society of the Red Cross and Red Crescent in Sierra Leone. It will not be possible to identify you in the results of the study when these are published. You

are entitled to receive information about the result/outcome of the study, if you are interested.

Right to access and right to delete your data and samples

If you agree to participate in the study, you are entitled to have access to the information registered about you. You are further entitled to correct any mistakes in the registered information. If you withdraw from the study, you are entitled to have your data deleted, unless the data have already been incorporated in analyses or used in scientific publications.

Voluntary participation

Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for your work or affiliation with the Red Cross and Red Crescent Society. If you wish to participate, please indicate this by signing the declaration of consent on the final page. If you agree to participate at this time, you may later on withdraw your consent without any consequences. If you later on wish to withdraw your consent or have questions concerning the study, you may contact the researcher as follows:

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Consent for participation in the study

I am willing to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed by the researcher, date)

Appendix 4

Project: Improving Disease Surveillance in Sierra Leone
Chief Investigator: Christina Brux Mburu
Reference: 2015/1686 D

Dear Christina Brux Mburu,

We are writing in reference to your Remit Assessment Form for the Research Project "Improving Disease Surveillance in Sierra Leone", received on the 10th of September 2015. The Form has been assessed by the Chair of the Regional Committee for Medical & Health Research Ethics of South East Norway, Section D.

The Ethics Committee System in Norway consists of seven Independent Regional Committees with authority to either approve or disapprove Medical Research Studies conducted within Norway, or by Norwegian Institutions, in accordance with ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act).

For the purposes of The Act, the following definition applies for medical and health research: activity conducted using scientific methods to generate new knowledge about health and disease, cf. § 4 of The Act.

The purpose of the abovementioned study is to "explore volunteer experiences with and perspectives on the system in Sierra Leone, with the goal of evaluating the existing system, identifying strengths and challenges, and enabling improvements in accordance with the local context and user needs".

REC considers the Research Project to be outside the remit of the Act on Medical and Health Research (2008), since it will not generate new knowledge about health and disease.

Even though the project can be implemented without the approval of the Regional Committee for Medical Research Ethics, it may be subject to rules regarding confidentiality and privacy protection, and local legal requirements. It is the obligation of the Institution Responsible for Research (the University of Oslo) to ensure that the project is conducted responsibly.

Please note that this conclusion is considered advisory according to the Act relating to procedure in cases concerning the public administration [Public Administration Act] cf. § 11.

Should you all the same want to send a full Project Application it will be evaluated in a Committee meeting and there will be made an individual decision in accordance with the Public Administration Act.

Yours faithfully
Ingrid Dønåsen
Higher Executive Officer
post@helseforskning.etikkom.no
T: 22845523

Regional komité for medisinsk og helsefaglig forskningsetikk REK sør-øst-Norge (REK sør-øst)
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Appendix 5

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Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

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Vår dato: 29.10.2015 Vår ref: 44752 / 3 / MSI Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 18.09.2015. Meldingen gjelder prosjektet:

44752

Behandlingsansvarlig Daglig ansvarlig Student

Improving Disease Surveillance in Sierra Leone: A Qualitative Study of Volunteer Experiences with Mobile Community Event-Based Surveillance systems

Universitetet i Oslo, ved institusjonens øverste leder Christina Brux Mburu Tine Mejdell Larsen

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31.

Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 30.06.2016, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Marte Byrkjeland

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

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Vedlegg: Prosjektvurdering

Kopi: Tine Mejdell Larsen t.m.larsen@studmed.uio.no

Personvernombudet for forskning

Prosjektvurdering - Kommentar

The sample will receive written and oral information about the project, and give their consent to participate. The letter of information is well formulated, but the supervisor's contact information should be added.

The Data Protection Official presupposes that the researcher follows internal routines of Universitetet i Oslo regarding data security.

Estimated end date of the project is 30.06.2016. According to the notification form all collected data will be made anonymous by this date. Making the data anonymous entails processing it in such a way that no individuals can be recognized. This is done by: - deleting all direct personal data (such as names/lists of reference numbers)

- deleting/rewriting indirectly identifiable data (i.e. an identifying combination of background variables, such as residence/work place, age and gender) - deleting digital audio and video files.

Prosjektnr: 44752

Appendix 6

GOVERNMENT OF SIERRA LEONE
Office of the Sierra Leone Ethics and Scientific Review Committee
Directorate of Training and Research,
Connaught Hospital
Ministry of Health and Sanitation

5th October, 2015

To: **Ms. Tine Mejdell Larsen (M.Phil Student)** **Principal Investigator**
Institute of Health and Society
Department of Community Medicine
Faculty of Medicine
University of Oslo
Norway
Email: t.m.larsen@studmed.uio.no
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Study Title:	**Improving Disease Surveillance in Sierra Leone: A Qualitative Study of Volunteer Experiences with Mobile Community Event-Based Surveillance Systems**
Version:	10 September, 2015
Committee Action:	Expedited Review
Master Programme Coordinator:	Terese Eriksen (University of Oslo)
Submission Type:	Initial version of study protocol submitted for review
Approval Date:	5th October, 2015

The Sierra Leone Ethics and Scientific Review Committee (SLESRC) having conducted an expedited review of the above study protocol and determined that it presents minimal risk to subjects, **hereby grants ethical and scientific approval** for it to be conducted in Sierra Leone. The approval is valid for the period, **5th October, 2015 – 4th October, 2016**. It is your responsibility to obtain re-approval for any on-going research prior to its expiration date. The request for re-approval must be supported by a progress report.

Review Comments:

- **Amendments:** Intended changes to the approved protocol such as the informed consent documents, study design, recruitment of participants and key study personnel, must be submitted for approval by the SLESRC prior to implementation.

- **Termination of the study:** When study procedures and data analyses are fully complete, please inform the SLESRC that you are terminating the study and submit a brief report covering the protocol activities. Individual identifying information should be destroyed unless there is sufficient justification to retain, approved by the SLESRC. All findings should be based on de-identified aggregate data and all published results in aggregate or group form.

Professor Hector G. Morgan
Chair

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