Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda

Report on anthropological research on the socio-cultural context of EVD in the most-at-risk districts in Uganda

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Executive Summary

On June 11th the Ministry of Health declared an epidemic of Ebola Virus Disease (EVD) in Kasese District, South West Uganda (MoH, 2019). This outbreak was traced in part due to the porous border between the DRC and Uganda, but also exacerbated by political instability in affected areas of the DRC where the epidemic has been ongoing since August 2018 leading to continuous influx of refugees to Uganda, low community engagement in Uganda's high-risk districts, and certain social and cultural norms related to Ebola prevention and control (MoH, 2018). Moreover, the Ugandan National Task Force on Disease Outbreaks and Response has cited an urgent need for a strategy for border health, cross-border cooperation, and scaled up risk communication among other priorities (See the 21st February and 14th March 2019 updates).

This research relied on anthropological methods to describe the social and cultural context of EVD prevention, transmission, and preparedness. Document analysis was conducted to survey the grey and published literature on Ebola, including documents from the Ugandan Ministry of Health, various Social Science Research Networks[1], and other researchers who had worked in recent Ebola epidemics. Key informant interviews (N=87) and focus group discussions (N=22 FGDs with 7-10 participants per group) were conducted in 5 different cultural groupings across 17 moderate and high-risk districts. Districts were grouped into five cultural groupings, namely: Bafumbira/Bakiga, Banyoro, Bakonzo/Batoro, Baganda and Lugbara/Alur; so that different cultural areas are sampled from to account for differences in the social and cultural context of EVD in Uganda and to capture a heterogeneity of settings. Different cultural traits exist between the five groups including difference in languages (dialects) spoken, farming practices (staple foods grown) and socialization such as marital rituals.

Together, this research informs EVD preparedness planning with information on community dynamics and cultural factors that may impact health seeking and preventive behaviors related to EVD. Further, this work will inform on possible areas of cultural resistance to

[1] Documents authored by researchers from networks and institutions concerning EVD such as report briefs produced by Social Science in Humanitarian Action Platform (SSHAP), Social Sciences Research Group (SSRG) linked to LSHTM, Bath, WHO, IFRC, MSF, UNICEF and GOARN (via WHO) and Social Science in the WHO's GOARN were accessed and reviewed.

information and social mobilization on EVD; how to leverage cultural assets in support of EVD risk communication; and finally, the cultural appropriateness and acceptability of EVD prevention and control activities. In other words, how do local Ugandans view Ebola? How do they respond to the threat of this virus? How do history, culture, politics, and economics influence their views of the disease? This research provides a missing part of the Ebola story, by situating narratives of local Ugandans in epidemic preparedness and control.

This report details the social, cultural, and behavioral factors associated with the EVD outbreak with implications for the national response efforts particularly risk communication and social mobilization activities and Ebola preparedness in Uganda. The findings are divided into the following sections:

- *Livelihoods and health*. Communities' and individuals' livelihoods impact their ability to seek health care, with implications for Ebola preparedness. In this context, livelihoods refer to economic modes of subsistence including market trading, cash crop agriculture, fishing, transportation, or small businesses. Livelihood strategies among our participants ranged, from fishermen to farmers, from long-distance truck drivers to *boda boda*[2] riders. The study revealed that although community members might be afraid of Ebola, they cannot easily change the way that they are behaving due to economic constraints. For example, *boda boda* riders still carry dead bodies from the DRC, despite knowing the risks, because they have to earn a living and cannot refuse the income that such work brings. Participants were struggling to make ends meet and therefore had limited capacity to make behavior changes such as taking a sick child to the hospital or limit movement into the DRC during the epidemic. Many described a limited capacity to change their behavior in light of their economic needs.

  The study noted a high level of regional connectivity, characterized here as circular movement with a high level of cross-border movement and socializing. For instance, Congolese come to Uganda to purchase merchandise, then return to the DRC shortly thereafter, and Ugandans go into the DRC to farm, for water or to trade at the daily and weekly markets, and then come back shortly thereafter. Notably, such livelihoods

[2] Boda boda riders in Uganda refers to motor cycle taxis

characterized with a need to cross the border several times a day while avoiding the bureaucracy at formal border points fueled reliance on informal border crossing points that are less equipped for EVD prevention. In summary, the populations inter-trade, inter-marry, and inter-socialize all of which present a major challenge to Ebola preparedness. These findings imply that risk communication should consider the ways in which individuals' livelihoods shape their capacity to make behavior changes.

- *Religious and traditional beliefs*. Religious (Muslim, Christian) and traditional (by cultural grouping) beliefs impact health-seeking behavior, including when to seek assistance from a traditional healer rather than from the formal health sector. Whereas religious and traditional beliefs varied by cultural grouping across all districts, communities practice a syncretic model of religious belief. For example, individuals may report being Catholic or Muslim, while also practicing their own local traditional faith. At times, these beliefs were alongside traditional spiritual beliefs as well - mixing the scientific with the spiritual. For example, one Imam encouraged the use of both Western medicine and spiritual healing side by side.

  Notably, in spite of the dualistic religious beliefs, communities demonstrated a high level of knowledge about Ebola - its origins, how to control for it, and what to do in case of a suspected case. Religious leaders report telling their communities to refer any suspected cases to health workers, demonstrating that educating religious leaders about EVD prevention would be an excellent way of disseminating Ebola information.

- *Burial practices and funeral rituals.* Burial practices are an integral part of cultural beliefs in each area studied and these practices may shift or not given Ebola risk. There are shared or similar rituals across several cultural groups and regions, where bodies must be returned to the ancestral land. Land ownership and paternity is intertwined with a sense of identity - both in life and in death. Communities will go to great lengths to ensure that in death the body's soul is at peace. For instance this might involve unusual transportation methods or dodging health workers as may have happened in the index cases of the current outbreak in Uganda. In the same vein, bodies are kept at home, and people spend the night with the body, keeping watch

over the body and its soul. Then, the body is prepared for burial - it is washed, cleansed, rituals such as dressing the body with jewelry or favorite embroidery are performed, and the burial takes place. Any safe burial practice must consider local practices, cultural norms, and beliefs beginning with the transportation of dead bodies, washing of dead bodies, and onto other rituals.

- *Caretaking practices.* Community and gender norms shape who takes care of who and how during times of illness. This was an important theme that emerged in other patriarchal societies, where the burden of care falls to women and therefore women are more vulnerable to Ebola. There is need to engage women and men differently, in modalities that take into account their differing gender roles in the home.

  Another significant factor, that seems to influence peoples' care-seeking behaviour, is their access to health care. Barriers for accessing health care at a private or public health facility include lack of money, logistical barriers where people describe dying trying to reach the health facility, and expected low quality of care at the facility. An alternative source of care was the use of traditional healers, shamans, and spiritual/faith-based healers who were reportedly more trusted than the biomedical public health workers. As such, the role of traditional healers in communities must be acknowledged and efforts should be made to engage them in Ebola preparedness work.

- *Health beliefs and health-seeking behavior.* Cultural and social beliefs shape decision-making around health as do access or distance to health facilities. Community members' future health decision-making appeared to be affected by previous poor experiences at health facilities. Community members differentiate between government and private health facilities - with government health facilities having the poorest reputation due primarily to health workers' attitudes and behavior toward patients. Additionally, pregnant women were reportedly very skeptical about some preventive measures such as hand washing in chlorinated water as they perceived it to potentially be harmful to their pregnancy. Thus during care seeking at the health facilities, they reportedly were reluctant to adhere to the preventive measures that involved hand washing being implemented.

- *Trust between the communities and authority.* The social and cultural context of trust between communities and authorities such as health workers and local leaders has implications for Ebola preparedness. Local leaders, particularly Local Council I[3] members, are seen as trusted and integral components of a community's fabric. Local leaders see it as a part of their job to ensure that Ebola does not reach the communities where they work. They only ask for additional support, messages, posters, and where needed, logistical materials such as bicycles, booklets and pens, to do this work. Where local leaders had been engaged, they emerged as an important group to disseminate information on Ebola prevention and control - spreading messages about hand washing, screening, and how to report a suspected case. In areas such as Arua and Pakwach, where less adequate Ebola preparedness work has been reported, local leaders were described as not really doing much.

  Responses on trust in authority differed regionally. Special attention must be paid to the dynamics in fishing communities, where trust in authority figures is very low - particularly trust in army soldiers. Due to the historical and political context in fishing communities (discussed in Section 4.9), fishing communities are wary of authorities. The wariness is in part related to the exorbitant costs of fishing, including loans[4] gone bad, and perceived injustices of fishing authorities. In these areas, trust in authorities is very low and many participants even expressed wishes that Ebola should "come there and kill them, so that they do not have to pay back loans they cannot afford". Importantly, a potential leverage point for Ebola preparedness is that fishing communities have got local leaders who could be engaged by response actors to participate and generate greater uptake of EVD preventive practices.

[3] In Uganda, communities are organized administratively under categories called Local Councils (LCs) to represent a given catchment population. There are five levels of Local Councils (LC I – LCV), with each higher level representing a greater population size. Each LC is led by a Chairperson (hence LCI Chair, LC II Chair up to LC V Chair) who heads a council that comprises of 8-10 members who represent different sectors including health.
[4] At the time of the study, participants in fishing communities reported that they had received loans to acquire boats to boost their fishing business. However shortly following acquisition of the boats, they were confiscated by the authorities and reportedly taken by uniformed personnel. That left fisher folk with both loans to pay and no boats to improve their fishing business.

- *Social, Political, and Economic Context.* The broader context shapes community's ways of coping with disadvantage and vulnerability, with implications for Ebola. This study identified particularly vulnerable communities due to experiences of structural violence - from rural poor to fishing communities. Issues such as lack of water and sanitation, other ongoing health threats (RVF, CCHF, etc.), lack of food stability, and poverty contribute to community vulnerability. In the refugee hosting districts that participated in the study conflict or discord between refugees and host communities could present a challenge to EVD preparedness and uptake of EVD messages.

Possible areas of cultural resistance to information and practices related to EVD prevention are highlighted, as are specific points of leverage (e.g. community/cultural assets) that can be used to support EVD preparedness. These include:

- Participatory social mobilization practices (e.g. involving local leaders) would ensure sustainability and uptake of EVD messages.
- Address stigma against Congolese, and emphasize that Ebola can be spread by anyone.
- Pay special attention to the local dynamics of landing sites, where fishing communities are in conflict with authorities. A primary goal of engaging these communities should be to foster peace and stability which are important not to derail any preparedness and response efforts as has been the case in DRC.
- Design posters for illiterate individuals, with well-designed photos to communicate messages; in additional local languages, and children-friendly messaging.
- Address the concerns of pregnant women and their issue with the Chlorine smell at hand-washing stations.
- Design youth-friendly mobilization practices, with the participation of local youth. Use song and dance to communicate messaging about Ebola.

Policy recommendations

In response to UNICEF C4D's support to EVD preparedness in Uganda's high-risk districts the following recommendations are provided:

(1) *Scale up risk communication to engage village health teams and Uganda Red Cross society volunteers to improve social mobilization at the community level.* This research will result in actionable steps to improve the cultural efficacy and uptake of risk communication messages. Further, this research will disseminate actionable and evidence-based steps to incorporate the social and cultural context of risk communication and social mobilization efforts. By examining leverage points within the community, this research will help to tailor EVD preparedness efforts.

(2) *Train additional teams that constitute local community citizenry for safe burials in high-risk districts.* By assessing existing burial practices and identifying leverage points for behavior change, this research will enable practitioners to encourage safe burial practices during times of high-risk of EVD transmission and whenever appropriate.

These findings align with the EVD Monitoring Framework (MoH 2018), specifically Result Areas 2 (enhanced community awareness) and 3 (case management, infection prevention, and safe burials.

On Risk Communication and Social Mobilization

- The preferred mode of communication is through the radio and mobile phones (e.g. through SMS). Radio communication bridges the gap for those who are unable to read due to low literacy levels. Visual (graphic/pictorial) communication should also be enhanced to increase the effect of communication and mobilization. Design posters for illiterate individuals, with well-designed photos to communicate messages.
- Specific "risk behaviors" for the spread of Ebola remain predominantly: high levels of migration and cross border travel, lack of frequent hand washing, traditional burial practices, health seeking behavior particularly use of traditional healers for treatment which encourages cross border movement.
- Translate messages into local languages and should offer solutions, and not just "practices to avoid". Our study calls this a "harm reduction" approach to Ebola preparedness. In other words, due to significant barriers (e.g. livelihoods) to taking up

Ebola prevention measures, it is important that we demonstrate ways to *safely* conduct burials or hunt for bushmeat. If we persist with a "stop" all behaviors approach, the uptake will be low and individuals will not comply with recommendations.

- Participatory social mobilization practices (e.g. involving local leaders) would ensure sustainability and uptake of EVD messages.
- Address stigma against Congolese, and emphasize that Ebola can be spread by anyone. One way to target this message is to remind communities of previous accounts of Ebola outbreak within Uganda including in Central Uganda (Luwero district), which is so far away from the DRC. This is especially important as the outbreak in Uganda emerges from the DRC, and with index cases being Congolese, would risk fueling negative perceptions about risk of infection associated with Congolese.
- Pay special attention to the local dynamics of landing sites, where fishing communities are in conflict with authorities. C4D teams need to design specific strategies to engage with this sensitive issue in hot spots like landing sites.
- Design messages to address the practice of self-medication from pharmacies and encourage reporting early on during symptom experience to health facilities.
- Design posters in additional local languages, and children-friendly messaging.
- Address the concerns of pregnant women and their issue with the Chlorine smell at hand-washing stations.
- Design youth-friendly mobilization practices, with the participation of local youth. Use songs, dances, and so on, to communicate messaging about Ebola.
- Engage Ebola survivors in spreading messaging in their communities. Congolese and Ugandan Ebola survivors from current or previous outbreaks can be sought for ‘peer’ roles in training and communication about the dangers, mishaps and desired treatment seeking experiences.
- Design risk communication that focuses on other symptoms and emphasizes that not all individuals with Ebola have hemorrhaging.

On Trusted Sources of Information

- Village Health Workers were also cited as a trusted source of information.
- Key influencers in border districts include: local leaders, NGO workers, private health workers, and religious leaders.

- Map community stakeholders in each community and engage those who are trusted.

On Caretaking Practices at Home and in the Community

- Mobilization of the community must be sensitive to local conditions, relationships and power dynamics. This includes using existing structure in the given area to deliver health messages. In some areas, this might mean to deliver health messages through the church whereas other structures might be more appropriate to use in other areas.
- Most health care and treatment take place at household level and is done by women. Health workers need to reach out and work close together with women in general and specifically in regard to Ebola prevention.
- Provide a hotline (cell phone/radio free of charge) to help women make decisions about care at home. For women who may not have access to a phone, designate other community members with phones whose routine community roles make them approachable such as the Village health team (VHT) members.

Care-Seeking Practices

- More needs to be done to engage traditional healers, particularly in rural areas where these individuals are the first point of care. The traditional leaders should be trained to function as positive agents for behavior change towards Ebola preparedness.
- Mapping of the different types of traditional healers to enhance collaboration with local leaders. This will both be beneficial in the preventive stage of Ebola but such mapping will also enhance an effective surveillance tool in case of an Ebola outbreak in Uganda.
- Training and engagement of more VHTs. Due to limited access to health care facilities VHTs are critical to enhance Ebola preparedness in hard to reach areas.

Adoption of Protective Behaviors

- Information towards adoption of protective behaviors should be authentic and pragmatic. For instance, to avoid creating fear of greeting friends and family members, the community including religious and local leaders should be engaged to develop alternative safe and cultural appropriate greetings.

- Enhance sensitizing and training targeting individuals working in the transportation sector (i.e. *boda boda* and *taxi* drivers) to bring attention to the risk of transporting dead bodies.

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List of Abbreviations

ADF	Allied Democratic Forces
C4D	Communication for Development
CAO	Chief Administrative Officer
CDC	US Centers for Disease Control and Prevention
CCCs	Community Care Centers
CCHF	Crimean-Congo Haemorrhagic Fever
DHEO	District Health Education Officer
DHO	District Health Officer
DRC	Democratic Republic of the Congo
ETU	Ebola Treatment Unit
EVD	Ebola Virus Disease
FGD	Focus Group Discussion
HBM	Health-Belief Model
UCRC	Uganda Red Cross Society
IDI	Infectious Diseases Institute - Mulago
LC	Local Council
KII	Key Informant Interview
MAKSS REC	Makerere University School of Social Sciences Research Ethics Committee
MoH	Ministry of Health, Uganda
NGO	Non-Governmental Organisation
NTF	National Task Force
POE	Point of Entry
RA	Research Assistant
RCSM	Risk Communication and Social Mobilization
REC	Research Ethics Committee
RVF	Rift Valley Fever
UNCST	Uganda National Council for Science and Technology
UNICEF	United Nations Children's Fund

UNMEER	UN Mission for Ebola Emergency Response (2014-2015)
USAID	United States Agency for International Development
VHT	Village Health Team
WHO	World Health Organisation

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Definitions

Emic refers to the ways in which individuals native to communities interpret the world around them. It is an "insider's perspective" - as it applies here, it is how a community (e.g. Rwenshama) perceives Ebola in Uganda (Harris, 1976).

Etic refers to the "outsider's perspective" - for example, how people from outside a community (e.g. researchers, UNICEF staff) perceive Ebola in Uganda (Harris, 1976).

Vulnerability is influenced by broader social and structural characteristics, whereby an individual's social position engenders unequal life chances (Rhodes et al., 2005). The vulnerability of persons to Ebola may be affected by causes far removed from the individual's control, but impact their lives through economic inequalities, sexism, discrimination, and so on (Sumartojo, 2000).

Illness experience differentiates illness from disease by describing the ways in which people define and adjust to interruptions in health. *Illness*, in medical anthropology, refers to a lay person's definition of a health problem, while *disease* refers to a professional definition of a health problem based on signs and symptoms (Scambler, 2015).

Agency refers to the individual expression of will, while *structure* might constrain that free will. Agency is the capacity of individuals to act independently and make free choices. Meanwhile, stable societal structures (e.g. educational, religious, political) limit the individual's ability to make choices. The debate between agency and structure questions whether individuals have autonomy or rather, if lives are constrained by a broader social structure. Related to Ebola, individuals might desire to stop traveling to high-risk areas of the DRC. However, due to a lack of financial stability, they may not be able to stop travelling to the DRC for business or other market opportunities. In this sense, *constrained agency* refers to what choices a person can make given their position in a society or on a social ladder (Giddens, 1984).

Part One: Background to the Study

1.1. Introduction

The epidemic of Ebola Virus Disease (EVD) that was declared in North Kivu Province on 1st August 2018 in the Democratic Republic of the Congo (DRC) is ongoing and has been declared in Uganda in June 2019 (Uganda MoH, 2019). The epidemic is continuing with 2108 cases and 1317 confirmed deaths in DRC reported as of 12th June 2019 (WHO, 2019). The current epicenters of the outbreak are in Butembo and Katwa Health Zones. While some progress has been made, there is still much more progress to attain the WHO's goal of ending the DRC outbreak within six months. Moreover, while the geographic scope of the epidemic has reduced, the intensity of the epidemic in its stronghold areas has increased and many people are no longer seeking care (IFRC, 2019). At the time of commissioning this study, it was vital that multisectoral actors on the Ugandan side remain vigilant and continue preparedness efforts due to the proximity of the DRC outbreak with several Ugandan districts.

This is particularly of concern due to the porous border between the DRC and Uganda, political instability in the affected area leading to continuous influx of refugees to Uganda, and certain social and cultural norms that may impede Ebola prevention and control (Uganda MoH, 2018). Moreover, the Ugandan National Task Force for Disease Outbreak and Response has cited an urgent need for a strategy for border health, cross-border cooperation, and scaled up risk communication among other priorities (See the 21st February and 14th March 2019 updates).

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groupings based on ethnicity and language/dialect across 15 moderate and high-risk districts. The five cultural groupings were Bafumbira, Banyoro, Bakonzo/Batoro, Baganda and Lugbara/Alur; representing the districts where participants were sampled from to account for differences in the social and cultural context of EVD in Uganda and to capture a heterogeneity of settings.

Together, this research informs EVD preparedness planning with information on community dynamics and cultural factors that may impact health seeking and preventive behaviors related to EVD. Further this work will inform on possible areas of cultural resistance to information and social mobilization on EVD; how to leverage cultural assets in support of EVD risk communication; and finally, the cultural appropriateness and acceptability of EVD prevention and control activities. In other words, how do local Ugandans view Ebola? How do they respond to the threat of this virus? How do history, culture, politics, and economics influence their views of the disease? This research provides a missing part of the Ebola story, by situating narratives of local Ugandans in epidemic preparedness and control.

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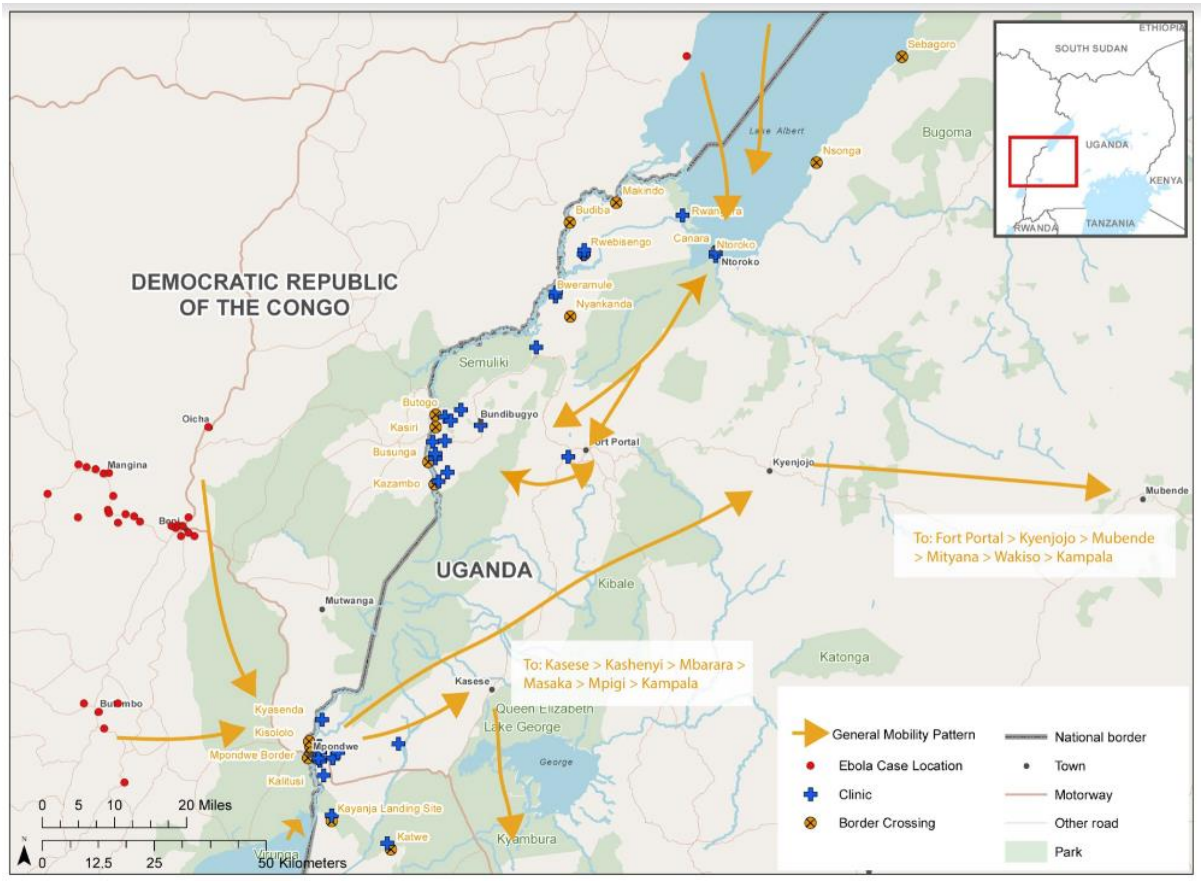
1.2. Ebola: The Current Epidemic in DRC

The epidemic of Ebola Virus Disease (EVD) that was declared in North Kivu Province on 1st August 2018 in the Democratic Republic of the Congo (DRC) is ongoing with moderate intensity and a case fatality ratio of 63% (WHO, 2019). Katwa and Butembo are the major health zones of concern (WHO, 2019) with an emerging cluster of cases in Mandima health zone (WHO, 2019). There is a high number of deaths reported among confirmed cases and persistent delays in detection and isolation, surveillance, and contact tracing (WHO, 2019). Many infections occur in hospitals (e.g. nosocomial infections), where isolation is delayed and cases are not handled in line with standard infection prevention protocols. Moreover, there is a potential risk for transmission of EVD across borders due to the fragile security situation and porous borders.

In the DRC, ongoing political instability threatens progress in epidemic control (Nguyen, 2019). In June 2018, the Kivu Security Tracker reported that in North and South Kivu, more than 140 armed groups were active. Armed groups such as the Mai Mai attack in Butembo earlier this year and the Allied Democratic Forces (ADF) operate in Grand Nord, facilitating access to the area (Social Science in Humanitarian Action Platform [SSHAP], 2018). This limits the movement of response teams, their ability to provide information, and to respond to the epidemic with surveillance and contact tracing (SSHAP, 2018). Moreover, just recently on 9th April 2019, it was reported that Ebola Treatment Centers were being attacked by armed groups in Butembo (Kivu Security Tracker, 2019). In Beni, where the Ebola epidemic was centered in DRC, the security situation was highly volatile with killings along major roads and violence on the outskirts of town. Similarly, during the recently concluded elections there was civil disturbance that resulted in attacks on and destruction of some PoEs. This ongoing security has implication both for the Ebola response and for cross-border movement, with a number of refugees continuing to cross into Uganda. The total number of Congolese refugees in Uganda is 326,383 as of 28th February 2019 (UNHCR, 2019).

Moreover, cross-border trade and movement continues unabated. Due to the high cost of goods in DRC, many traders cross into Uganda to purchase goods. Simultaneously, Ugandan traders cross into DRC with their goods. Along the border areas, movement is constant and not limited by the epidemic.

Figure 1. EVD Cases in the DRC plus Movement (CDC, 2019)



Cross border movement between DRC and West Nile region of Uganda is very high. It comprises movement ranging from more affluent traders who travel by air from major towns in DRC such as Goma, into Arua in North West Uganda and onwards to Entebbe. Additionally, there is cross border trading on small scale involving hawkers who cross the border several times daily and other livelihood related movement (such as for health and schooling) between the border areas of West Nile (e.g. Zombo district) and neighboring DRC. Another source of heavy marine traffic occurs along Lake Albert particularly among both Ugandan and Congolese fisher folk. Together, this movement pauses a great risk for the spread of EVD.

1.3. Ebola: A History in Uganda

The Ministry of Health, Uganda categorized the entire country into three risk categories. Category one districts are considered to have an elevated risk of Ebola importation. There are twenty high-risk districts with direct links with affected health zones in Ituri and North Kivu provinces and refugee hosting districts close to the affected areas. The districts include: Ntoroko, Kasese, Kabarole, Bundibugyo, Bunyangabu, Kanungu, Kisoro, Rukungiri,

Rubirizi, Kikuube, Kamwenge, Kyegegwa, Kyenjojo, Isingiro, Buliisa, Hoima, Kagadi, and Pakwach. The population-dense location of Entebbe International Airport and migration-destination areas of Kampala and Wakiso are classed as category one districts (Ministry of Health, 2018). Category two (moderate risk) districts include Arua, Maracha, Nebbi, Zombo, Yumbe, Moyo, Adjumani, Koboko, Lamwo, and Kabale.

Uganda has a history of Ebola outbreaks, including: 1) June 2019 in Kasese; 2) Oct 2000 - Jan 2001 in Gulu, Masindi, and Mbarara; 3) Dec 2007 - Jan 2008 in Bundibugyo; 4) 2011 and Jun-Aug 2012 in Luweero; and 5) 2012 in Kibaale (Ministry of Health, 2018).

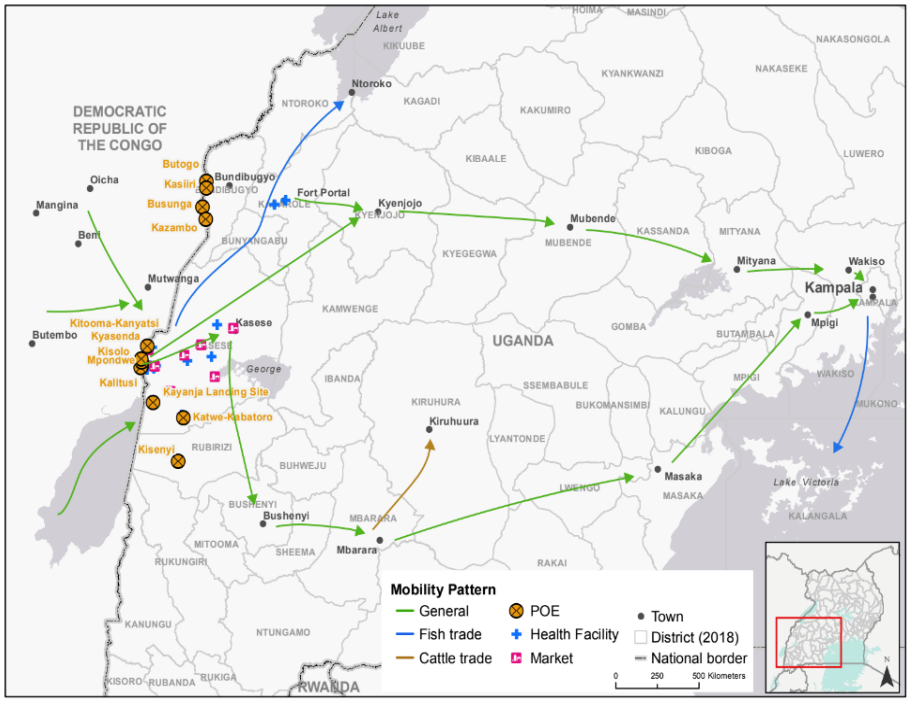
Table 1. From the Uganda MoH's National EVD Contingency Plan (2018)

Table 1: EVD preparedness and response to the previous EVD outbreaks in Uganda

EVD indicator *(Outbreak/ Timeliness/ Effectiveness)*	**Gulu,2000**	**Bundibugyo,2007**	**Kibaale, 2012**	**Luwero, 2011**	**Luwero, 2012**
Days from onset of first Ebola signs in the index case to reporting to MoH	20	51	30	NA	24
Days from reporting of first case to picking of sample for EVD diagnosis	3	2	1	NA	1
Days from picking of sample to EVD confirmation	2	7	14	NA	4
Days from EVD confirmation to declaration of national action	1	1	1	NA	1
Days from onset of first EVD signs in index case to declaration of national action	26	61	46	NA	30
Total confirmed cases	425	149	15	1	7
Total confirmed deaths	224	37	4	1	4
Case Fatality Ratio (%)	53	25	27	100	57
Duration of the epidemic	117	101	63	NA	34

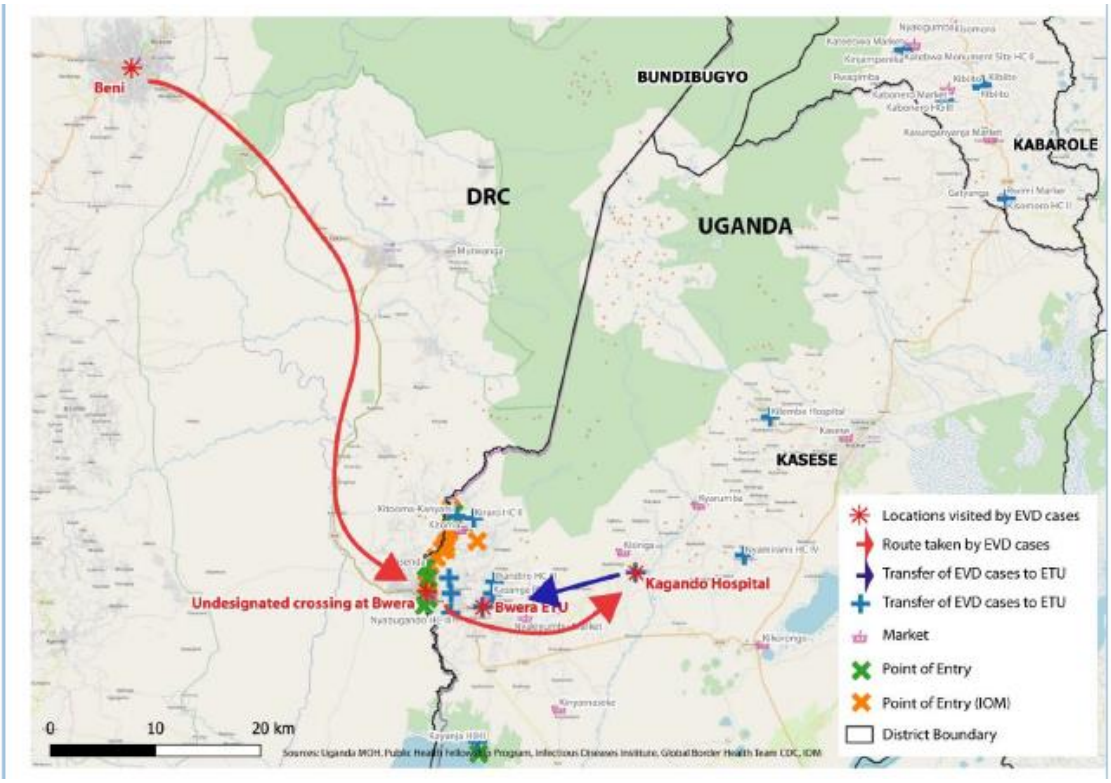
This demonstrates the country's high-risk and the potential for an indigenous outbreak to come up. The 2000-2001 Uganda outbreak was one of the largest Ebola outbreaks, with 425 suspected cases and 224 deaths, or a case fatality rate of 53% (Hewlett & Hewlett, 2008). The outbreak was first identified at a Catholic Hospital in Gulu, and most cases occurred in urban centers (Hewlett & Hewlett, 2008). As in previous urban Ebola outbreaks, local hospital care amplified transmission due to a lack of isolation wards, and improper application of infection prevention and control protocols (Hewlett & Hewlett, 2008, p. 39). Moreover, this outbreak occurred at the backdrop of insecurity from the Lord's Resistance Army insurgency in the North of Uganda, which affected mainly one ethnic group, the Acholi. Notably there were cases in Masindi and Mbarara in spite of the limited movement of people to the Northern region at the time.

Figure 2. Movement of People DRC-Uganda (CDC, 2019)



Much of the current risk stems not from an indigenous outbreak, but from transmission across the border. Along porous borders between the DRC and Uganda, thousands of people cross each day - for family functions, for market trading, to purchase goods, to sell goods, to fetch water, and so on. People marry, trade, socialize, and cultivate land across the borders. In other words, life does not stop because there is an international border. The border is a meaningless boundary, and therefore, it is of the utmost importance that Ebola preparedness is comprehensive in border districts. The following map illustrates movement of people across the DRC-Uganda border in the Kasese region. From the map, it is predictable that the most likely hotspot where risk of EVD transmission by a person crossing from DRC would emerge around Kasese's porous, informal crossing points. Such informal crossing points provide the least inconvenience associated with the preparedness activities at formal POEs.

Figure 3: Movement of EVD cases from DRC into Uganda (MOH, 2019)



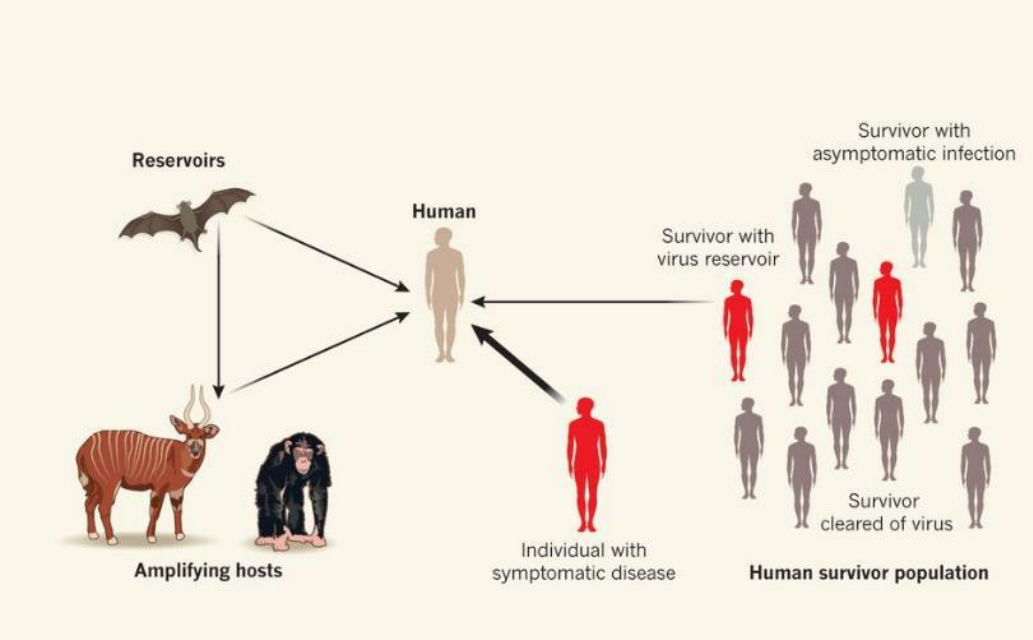
1.4. Literature Review

1.4.1. Ebola: A Brief Virologic Overview

Before we delve into the anthropological aspects of Ebola, it is important to establish a working definition and etiology for the disease. Ebola Virus Disease (EVD) is a deadly disease that most commonly affects humans and nonhuman primates (e.g. monkeys, gorillas, and chimpanzees) (CDC, 2019). First discovered in 1976 near the Ebola River in the Democratic Republic of Congo, the virus has led to several outbreaks over the past several decades. Four strains of Ebola, including Ebola virus (*Zaire ebolavirus*), Sudan virus (*Sudan ebolavirus*), Tai Forest virus (*Tai Forest ebolavirus*), and Bundibugyo virus (*Bundibugyo ebolavirus*) cause disease in human populations (CDC, 2019).

Ebola virus spreads to people from an animal host and then spreads throughout human populations.

Figure 4. Ebola reservoirs (from Heeney, 2015)



This can happen when someone touches infected body fluids or objects contaminated with fluids, and then the virus enters through broken skin or mucous membranes in the eyes, nose, or mouth. Ebola can also spread through direct contact with the blood, body fluids, or tissues of infected fruit bats or primates. Finally, people can get the virus through sexual contact (CDC, 2019). Ebola is spread through direct contact with:

- Blood or body fluids (urine, saliva, sweat, feces, vomit, breast milk, semen) of a person infected with Ebola;
- Objects that are contaminated with body fluids from a person infected with Ebola;
- Infected animal hosts, such as fruit bats or primates;
- Semen from someone who has recovered from Ebola up to 9 months post-recovery.
- The breastmilk of a mother who is sick or has recovered from Ebola
- Ebola positive mothers may pass the virus on to their unborn children

Individuals are not contagious until they become symptomatic. In other words, Ebola cannot spread until a person develops signs or symptoms of Ebola (CDC, 2019). The incubation period of Ebola is 2 to 21 days. Early symptoms include a sudden onset of fever, fatigue, muscle pain, headache, and sore throat (WHO, 2018). The later-stage symptoms include vomiting, diarrhea, rash, impaired kidney and liver function, and occasionally, internal and external bleeding (WHO, 2018). Due to the commonality of these symptoms with other febrile illnesses diseases such as malaria, typhoid fever, and meningitis, Ebola is often missed at first examination and particularly in the absence of a laboratory test.

Ebola treatment depends on early referral to a hospital or Ebola Treatment Center, for supportive care, rehydration, and treatment of symptoms (WHO, 2018). Early referral and appropriate management improves Ebola survival outcomes, and when paired with isolation of the sick, ensures that the disease does not spread further.

The roll-out of Ebola vaccines is a newer strategy to contain the epidemic. An investigational vaccine called rVSV-ZEBOV has been shown to be safe and protective against Ebola-Zaire and has been recommended by the Strategic Advisory Group of Experts on Immunization (Strategic Advisory Group of Experts, 2017) for use in Ebola outbreaks. The vaccine contains an animal virus (vesicular stomatitis virus) that causes the flu in humans and has been genetically engineered with an Ebola-Zaire protein to create an immune response (WHO, 2018). Ring vaccination is currently being conducted in the DRC, which involves contact tracing, recruiting individuals at a raised risk of infection, and vaccination of contacts of known victims and their contacts. These individuals include health workers and frontline

workers in contact with Ebola patients, or individuals who came in contact with an Ebola patient in the last 21 days. However, in the DRC, the National Regulatory Authorities and the Ethics Committee excluded women who are pregnant and children under one year of age (WHO, 2018). On February 20, 2019, officials advising the DRC Ministry of Health changed positions on this, and now vaccines are offered to all (Krubiner, 2019). The "ring" refers to the social network of individuals and areas where the index patient spent time while symptomatic with Ebola (WHO, 2018).

1.4.2. Anthropology of Infectious Disease

Anthropological studies of infectious disease are situated within broader and often interdisciplinary work on the prevention, treatment, and control of epidemics. Anthropological approaches are well-placed to engage with studies of infectious disease, which may be symptomatic of underlying social, economic, and political conditions. Under this broad umbrella, anthropological approaches include the evolutionary, biocultural/biosocial, and political-economic.

Armelagos, Brown, & Turner (2005) discuss the evolutionary and political-economic approaches to health and disease. Placed in a historical context, the origin and rise of social inequalities beginning with the Neolithic Revolution has dramatically shaped the structuring of society and differential life chances as related to health outcomes (Armelagos, Brown, & Turner, 2005). Omran's (1971, in Armelagos et al., 2005) epidemiological transition theory characterizes three major periods of change throughout human history. First, Omran (1971) identifies the role of the Neolithic Revolution in social stratification, combined with rapid urbanization and the rise of infectious disease. Then, with industrialization, many industrialized societies saw a shift to a larger burden of chronic disease. Finally, reconfigured global spaces have produced the reemergence of infectious diseases. This combines with antibiotic resistance, increasing inequality, and environmental degradation and more broadly climate change issues. However, these are over-arching generalizations that often mask the heterogeneity within each category or place. While these transitions are conceptually useful, it is important to note the many countries that did not pass through these stages – some did not or have not experienced large-scale industrialization. Others experience a double burden of infectious *and* chronic disease. The role of political and economic factors is further

elaborated by Armelaogs et al. (2005), as rising inequality and social stratification has been a major driver of health and disease.

A concept of *syndemics* demonstrates the synergistic interaction of two or more diseases due to the clustering of social and economic factors such as job scarcity (Singer, 2015). A *syndemic* approach derives from Critical Medical Anthropology and contributed an articulation of the social origins of disease in a global economic system, the analysis of health policies, a placement of micro-level behavior in wider contexts, and critiques of health programs (Singer, 2015). Four levels of interface are key, between humans and the physical environment; between disease and human host; interactions among diseases within a host; and interactions between social systems, inequality, and the environment (Singer, 2015, p. 199).

The CDC (2012) relies on a syndemic framework when describing the interaction and clustering of HIV and TB, particularly in low-income populations (Singer, 2015, p. 209). Here, as Singer (2015) points out, it is the *interaction* of HIV and TB that is so damaging and deadly, preying on marginalized people. The clustering of social, economic, and health outcomes (Singer, 2015) demonstrates the biosocial aspect of diseases such as HIV/AIDS. Less present in syndemic approaches are explicit critiques of neoliberal policies, global institutions, and the role of global processes in local inequalities. Further, a syndemic approach often obscures the role of human agency – relying more on deterministic frameworks. A syndemic framework did, notably, contribute foundational analyses of social and economic clustering and patterning of disease.

So, what is anthropology's role in the study, prevention, treatment, elimination and eradication of infectious disease? What does the discipline offer? To begin, it is important to note that infectious disease is often symptomatic of underlying social disadvantage – both on a global and a local scale. Moreover, anthropologists are often working at the margins of society, in places where infectious disease is prevalent and a main contributor to morbidity and mortality. Romero-Daza & Himmelgreen (1998) identify the role of migrant labor in the HIV epidemic in Lesotho. This article also discusses the role of concurrent sexual partners – unfortunately, a too-often cited stereotype of the "African" HIV epidemic. Nonetheless, the situating of HIV within a context of migration (both male and female), economic precarity, substandard housing, sex work, and broader ill-health highlights the importance of taking a

political-economic approach to infectious disease. HIV, particularly, is emblematic of the confluence of historical, political, economic, and social factors that contribute to differential vulnerability across and within populations. To speak to HIV, one must address these broader structural factors.

The case of H5N1 in Central Java (Padmawati & Nichter, 2008) represents one example of infectious disease threats to global health and biosecurity. Padmawati & Nichter (2008) rightly focus on the political and social dimensions of Indonesian society, to elaborate an understanding of the spread of disease. Ebola presents another unique and imperative case – both of anthropological involvement in infectious disease, and of the underlying political, colonial, and social factors (S. A. Abramowitz, McLean, et al., 2015; Martineau, Wilkinson, & Parker, 2017). Abramowitz and colleagues examine how anthropology came to serve as a marker of solidarity with local populations, respect for local practices, and situational political realities during the Ebola epidemic in West Africa in 2014 (S. Abramowitz et al., 2017). The global response to Ebola was perhaps grounded in fear – fear of the virus (it is hemorrhagic and deadly), fear of it crossing borders (e.g. via a human host traveling to the US/Europe from West Africa), and perhaps fear-driven local responses to outside intervention (e.g. local responses to contact tracing and response teams).

Throughout the West African Ebola epidemic, anthropologists sought to involve qualitative and anthropological approaches in epidemic control efforts. Four overarching pillars of the response included contact tracing, isolation and quarantine, social mobilization, and safe burials (S. Abramowitz et al., 2017). Anthropologists emerged in solidarity with local populations in a sort-of activist positioning, particularly around sensitive issues like isolation and quarantine, and safe and dignified burial of the dead (S. Abramowitz et al., 2017; Martineau et al., 2017). Further, theoretical innovations emerged from anthropological work during the epidemic – around conceptualizing multispecies, ecological approaches to transmission (Brown & Kelly, 2014 in Abramowitz, 2017, p. 435), around narratives of crisis and resolution (Desclaux & Sow), and around racist and primitive discourses (McGovern, 2014 in Abramowitz, 2017, p. 435). While these theoretical contributions are notable, it will be important to leverage anthropology's foundational and critical work on political and economic factors that structure epidemics.

1.4.3. Ebola: Historical, Social, and Cultural Context

In the DRC as well as in other EVD outbreaks or epidemics, socio-cultural factors have been linked to EVD spread in the published and grey literature. These factors include a mistrust of health workers (S. Abramowitz et al., 2017; S. A. Abramowitz, Bardosh, et al., 2015; Leach & Wilkinson, 2014; Omidian, Tehoungue, & Monger, 2014) that is linked in part to wider mistrust of authority including government enforcement agencies, refusal of vaccination, loss to follow up of contacts and a refusal or low uptake of safe burials (Moran, 2017; Nielsen et al., 2015) both of which are associated with fleeing to other areas and thus setting up new chains of transmission. Other factors that influence EVD spread such as women's caretaking practices (Ravi & Gauldin, 2014), religious beliefs (Marshall & Smith, 2015), and so on, are also important consider.

Fear influences individual behaviors and community responses in powerful ways - from a fear of Ebola, to a fear of Ebola containment practices, a fear of national governments, international institutions, and global spread of the virus (Shultz et al., 2016a). Fear and mistrust manifest in community's resistance to containment and prevention efforts. However, theories that local community's fear and mistrust result in Ebola denialism tell only a part of the story (Bolten, 2014; Epstein, 2014). These reductions remove analyses from their historical, political, and social framing (Wesley, 2014).

"Community resistance" is another way of framing the complicated aspects of low uptake of Ebola control and prevention measures. However, *community resistance* is itself poorly defined and measured (S. Abramowitz et al., 2017). Further anthropological research is needed to unpack this terminology and situated it in a historical and social context. Anoko's (2014) work in Guinea examined efforts to safely bury a pregnant woman who had died from Ebola. Meanwhile, Faye (2015) looked at Guinean communities and their acceptance of WHO response teams. Anthropologists have been helpful in facilitating dialogues and building relationships to challenge rumors (Hewlett & Hewlett, 2008; Wilkinson, 2014).

In the West Africa epidemic, a lack of trust in health workers and the health system was often cited as a reason for Ebola's spread (S. Abramowitz et al., 2017). In December 2014, the director of the WHO Margaret Chan talked about a 'lack of trust in governments', while *The Lancet's* Editor-in-Chief wrote how Ebola is symptomatic of the '...breakdown of trust

between communities and their governments." A mistrust of health workers during Ebola crises has long been documented by anthropologists (Fallah, Skrip, Gertler, Yamin, & Galvani, 2015) Minor Peters, 2014). This mistrust creates conditions for the perception that a community is resisting Ebola efforts (Martin et al., 2016; Wilkinson & Fairhead, 2017) Fairhead, 2016; Martin et al., 2016).

Vaccine refusal is increasingly reported as a barrier to Ebola containment in DRC (Al-Jazeera, 2019; WHO, 2018). The WHO defines *vaccine hesitancy* as a "delay in acceptance or refusal of vaccines despite availability of vaccination services." It is a complex and context-specific phenomenon including factors such as complacency, convenience, and confidence (WHO, 2018). A recent survey in the DRC (Vinck, Pham, Bindu, Bedford, & Nilles, 2019) highlighted the practical implications of mistrust for Ebola control. Factors such as low belief in Ebola origins and low institutional trust were associated with a decreased likelihood of adopting Ebola vaccines (odds ratio 0.22) and seeking formal health care (odd ratio 0.06) (Vinck et al., 2019). Additional research is needed to investigate the social and cultural context of vaccine hesitancy in the DRC and other at-risk countries.

"Additional research is needed to investigate the social and cultural context of vaccine hesitancy in the DRC and other at-risk countries."

Safe and dignified burials were an established part of the West African Ebola response, but despite these recommendations, unsafe burials persisted (S. Abramowitz, 2017; S. Abramowitz et al., 2017). Anthropologists have long been involved in documenting funerary practices and rituals around the world. Related to Ebola, anthropologists documented how to deal with challenges in managing safe burials (Johnson et al., 2015; Whitty, 2017). Moran (2016) explains how the movement of bodies and finances play out in local informal economies of body preparation, burial, memorials, and graves. Fairhead, Richards, and Mokuwa discussed the religious and social significance of burial rituals (Fairhead, 2014; Fairhead & Richards, 2014; Richards & Mokuwa, 2014). Guidance was created to incorporate local cultural knowledge of burial practices and to improve uptake of safe burials, helping to reduce conflict with the communities (Lipton, 2014; Saéz & Borchert, 2014). These efforts resulted in a revision of protocols for training burial teams, the incorporation of local actors in safe burial practices, and expanded trainings for health care workers and community mobilizers (S. Abramowitz, 2017).

If you are a woman of reproductive in an Ebola-affected country right now, you face a triple threat: You could die from Ebola, you could die during pregnancy or you could die during childbirth. Ebola is affecting women at much higher rates, because women are traditionally caregivers, and we also know that if you're pregnant, fatality rates for Ebola are much higher – 95.5 percent (Strong et al., 2019). So, for pregnant women, Ebola is almost a death sentence. Ebola vulnerability is also contoured by social and gender norms of caretaking. In many patriarchal societies, the burden of taking care of the sick and the young falls to girls and women. Anthropologists demonstrated that Ebola transmission was gendered due to culturally-prescribed caregiving roles, falling mostly onto women (Muhlberger et al., 2015; Sierra Leone Ministry of Social Welfare, Gender, and Children's Affairs et al., 2014). There is no biological difference regarding vulnerability to Ebola, yet 70% of Ebola-affected individuals during the 2014-15 West Africa epidemic were women. Harman (2016) argued that women were visibly affected by Ebola, but they were "invisible" at every point in the international response to the outbreak. In fact, the gendered impact of the disease did not frame responses in the 2014-15 epidemic (Davies & Bennett, 2016). Indeed most victims of the current outbreak in DRC and Uganda are women (WHO, 2019).

Anthropologists have worked to include informal and traditional health practitioners in the Ebola response (McLean et al., 2016; Pontarello, 2015; Wilkinson et al., 2014). Informal healers might include female chiefs, traditional birth attendants, or traditional healers (Manguvo & Mafuvadze, 2015). Informal healers are often the first point of contact during times of illness, particularly when a disease is believed to have a spiritual component, which the haemorrhage and other scary end stage symptoms of Ebola may evoke. Traditional healers are also socially important figures with wide social networks that can be leveraged to spread information about Ebola prevention, care, and treatment practices (UNMEER & Emergency Ebola Anthropology Initiative, 2014). Rather than sidelining traditional healers, they must be incorporated into existing risk communication and social mobilization practices to ensure more sustainable uptake of information by the community.

Social scientists have been a critical aspect of Ebola response, particularly starting in the 2014-2015 West Africa epidemic. Anthropologists have been crucial in identifying that social mobilization and community engagement efforts are rarely seen as positive by local communities (Wilkinson, 2017). Community engagement needs to be authentic and pragmatic, employing what we can call a "harm reduction" approach to Ebola prevention. It

must be sensitive to local conditions, relationships, and power dynamics (Chandler et al., 2015). In West Africa, participatory problem solving aided in a democratization of the epidemic response and ensured sustainable engagement of communities (UNICEF Program Division, 2014). Additionally, researchers demonstrated that a community-based model of care called community care centers (CCCs) that provide free health care, food, testing within communities were popular and effective as first-line triage systems (Abramowitz et al., 2015a,b; ICAP, 2015; Kucharski et al., 2015; Logan et al., 2014; Pronyk et al., 2016).

Meanwhile, community fear for or concerns with risk communication and social mobilization activities was also experienced in past epidemics. Anthropologists have managed tense situations between health workers and communities, serving as an interlocutor able to facilitate dialogue and build relationships to challenge rumors and change behavior (Wilkinson, 2014). Burial of the dead, for example, presents a long-standing challenge to Ebola response efforts. Despite a "safe and dignified burial" approach, communities often seek to bury their own dead due to a persistence of local cultural beliefs and practices. The religious and social significance of burial rituals has been well-documented with implication for Ebola control, ultimately helping to mitigate community-situated conflict (Sáez & Borcher, 2014; Fairhead, 2014).

Moreover, historical analyses have documented the types of structural violence that fuel community resistance to Ebola control efforts (Benton & Dionne, 2015; Wilkinson & Leach, 2014). Geopolitical realities shape Ebola responses, as we are seeing in the DRC outbreak - where a longstanding history of conflict is shaping health workers' ability to establish rapport with communities (WHO, 2018). An understanding of the historical geography of an area enables us to better shape response and preparedness efforts, rather than a one-size-fits-all approach.

It can be argued that as soon as the EVD outbreak occured, it became a human rights crisis. Or it could be argued from the natural resource rights movement – that it was a human rights crisis from day one. In the UN mission for Ebola Emergency Response (UNMEER) External Situation report dated 17 October 2014, As UN High Commissioner on Human Rights, Zeid Ra’ad Al Huseein, stressed that a disregard for human rights to things like health, education, sanitation and good governance had allowed Guinea, Liberia, and Sierra Leone to become fertile ground for the outbreak in the first place. Many researchers are

connecting deforestation in countries such as Liberia to the disease, citing that the change in landscape is bringing wildlife closer to humans. The virus is typically found in wildlife and transmission from animals to humans through contact with infected bodily fluids, causing a "spillover" in species (WHO, 2019). The virus can also be contracted from another human being when a person is in direct contact with infected bodily fluids during contagious periods. Among other causes, "seasonal droughts, strong winds, thunderstorms, landslides, heat waves, floods and changed rainfall patterns," are also accused of instigating wildlife migration away from their natural habitat to human proximity. The Wildlife Conservation Society (WCS) argues that Ebola outbreaks mostly occur after "unusual downpours or droughts in central Africa—a likely result of climate change." (D'Alessandro, 2014). Climate change would in turn amplify food insecurity, and prompt even more remote African communities to eat virus-carrying animals like bats.

The Ebola virus is known to spread into human populations through contact with an infected animal. The virus can live for years in animal populations (such as bats and monkeys) without harming the animals, becoming dangerous to humans only when humans prepare and eat infected bush meat. Poorer populations, living in resource-strapped areas, are the most likely to become stricken with the virus—because they are the ones most likely to rely on bush meat to feed their families. Additionally, according to the 2013 IFPRI report, poor communities bear the brunt of climate change. The report further argues that these communities become more needy thus encroach further into the wild in search of food. Such changes in human behavior, the report argues, likely impact the natural environment despite it still being unclear whether there would be a net positive or net negative impact (Wolfson, 2014).

We used this past work to inform current research in Uganda in high-risk districts during this critical window of time. In this pre-crisis phase in Uganda, we see an opportunity to prepare and produce risk communication and social mobilization activities that are locally relevant. Further, this research will build strong stakeholder relationships and collaboration and build trust with key players. This is an essential process that needs to start in anticipation of any potential threat (Figueroa, 2017). By anthropologically assessing the context of EVD, it is possible to culturally inform behavior change as has been done in

"In this pre-crisis phase in Uganda, we see an opportunity to prepare and produce risk communication and social mobilization activities that are locally relevant."

previous epidemic situations (Abramowitz, 2017). Moreover, it is imperative that the EVD preparedness and response in Uganda is tailored to the socio-cultural context of the high-risk region, with implication for improved EVD preparedness, better individual health seeking, and EVD prevention.

Part Two: Problem Statement, Objectives, and Frameworks

2.1. Purpose of the Research and Theoretical Framing

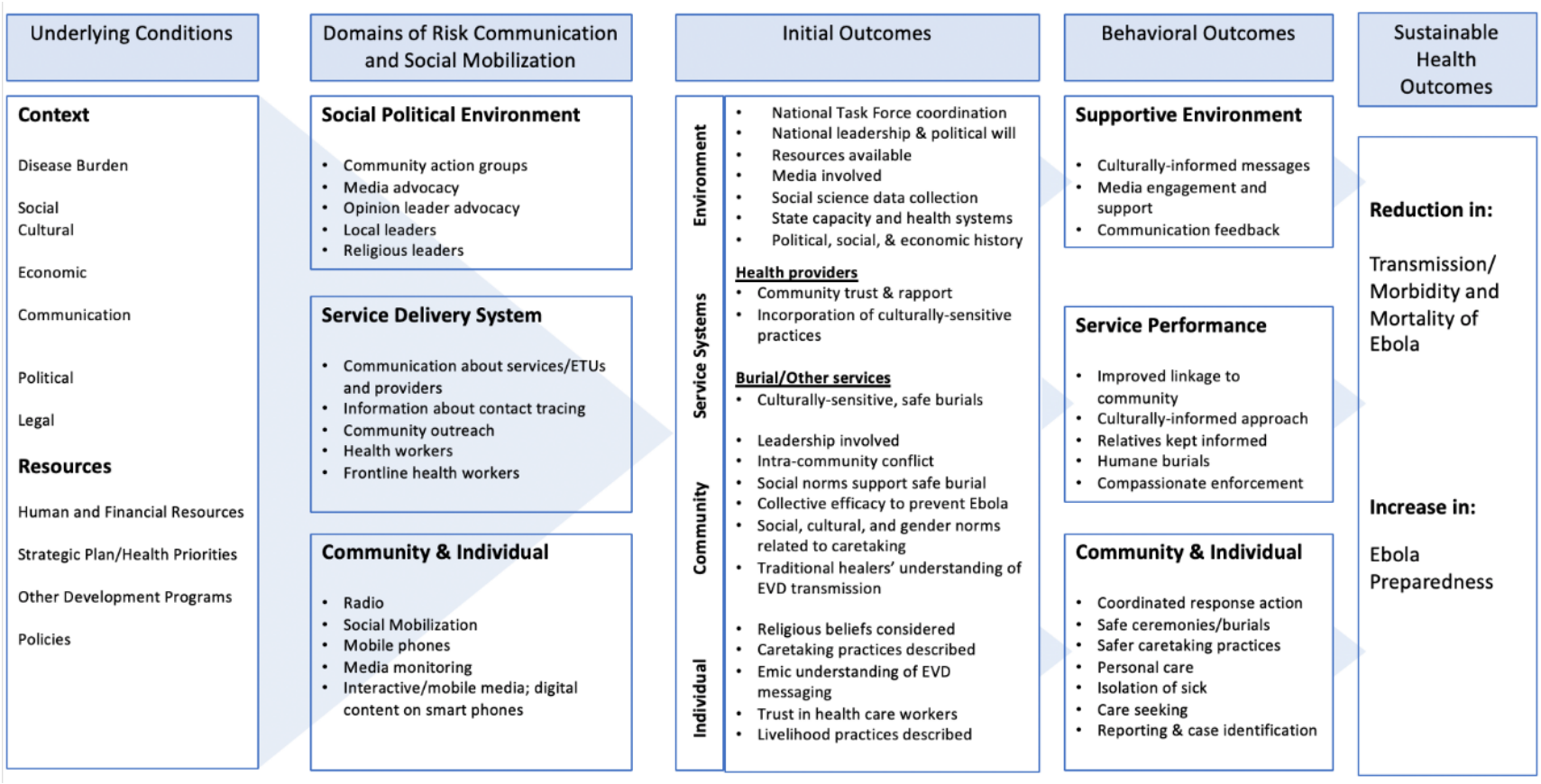
The overarching goal of this study was to describe the social and cultural context of health-seeking and preventive behaviors that may impact EVD preparedness, in order to inform EVD preparedness planning processes that focus on high-risk districts. This research relied on a socioecological model of communication and behavior that has proven empirically effective in past Ebola containment in West Africa (Figueroa, 2017). This model is a theory-based framework for understanding the multifaceted and interactive effects of personal and environmental factors that determine behaviors, and for identifying behavioral and community leverage points for health promotion and behavior change (CDC, 2014). Applied here it recognizes the interlinking levels of influence on behavior. Anthropological approaches are well-suited to tackling these kinds of complex issues, particularly with regard to EVD containment and preparedness. An overarching model adapted from the CDC (2014) is framed here (Figure 2.1.1.):

Figure 5. Socioecological model of communication and behavior (CDC, 2014)

This model was tailored to the Ugandan context, based on socioecological work by Figueroa (2017), by EVD work by Abramowitz and colleagues (2015; 2017), and by EVD work in Uganda by Hewlett (2003; 2007).

In our hypothesized model, we focus on social and cultural leverage points that are hypothesized to influence risk communication, social mobilization, and other EVD preparedness. In this model, we rely on the interconnectedness of an ecological model as illustrated in figure 2.

Figure 6. ***Socioecological Model of Communication and Behavior Adapted to Anthropological EVD Research***



"This model highlights four specific domains that have been shown to impact social and behavior change: policy, service delivery, community, and the individual."

This framework provides a useful lens to examine factors that might lead to effective prevention behaviors and is adapted from the work mentioned above (Abramowitz, 2017; Figueroa, 2017; Hewlett, 2003). This pathways framework was first developed for the USAID-funded Health Communication Partnership (2002-2007) project. In line with a socioecological model, it highlights four specific domains that have been shown to impact social and behavior change, from a risk communication perspective: policy, service delivery, community, and the individual. This model implies pathways leading to theory-based outcomes, to behavioral outcomes, and to desired health change. We first identified the preventive behaviors that need to be addressed, based on the literature and our own experience as anthropologists in Uganda, and then mapped the variables that potentially influence such behaviors.

2.2. Research Objectives

The research specifically sought to accomplish the following objectives:

1. To describe community perceptions and behaviors that are related to or can impact the EVD preparedness and response, specifically using applied anthropological research that contextualizes perceptions, livelihoods, health-seeking, funeral and burial practices in high-risk districts in Uganda.
2. To understand the relationship between community members and local, district, and national stakeholders in order to identify leverage points for strengthening community rapport and trust in stakeholders for better EVD preparedness in Uganda.
3. To document the policy and enabling environment of EVD preparedness in Uganda.
4. To facilitate the integration of sociocultural and other contextual issues in risk communication, social mobilization, and community engagement activities under the umbrella of EVD preparedness in Uganda.

2.3. Research Questions and Variables

The research addressed these key questions:

1. How might livelihood practices, religious beliefs, funeral and burial practices impact EVD preparedness and response and EVD spread in high-risk districts in Uganda?
2. How are local, district, and national stakeholder efforts in EVD preparedness received at the community level? What points can be leveraged for improved rapport and trust in stakeholders? How is EVD messaging perceived by the community?
3. What aspects of the social, political, and economic context might impact EVD preparedness and EVD spread in Uganda?

Study categories and variables are presented in Table 1 below. These variables derived from the literature and researcher experience as depicted in Figure 2. Methods are further detailed in the next sections.

Table 2. Study categories and variables

Individual-level Category	Operational Definition (Variables)	Data Collection Method
Religious beliefs & safe burial practices	Community religious beliefs related to EVD origin, transmission, prevention, and control, emic explanatory models for EVD (see Hewlett & Amola, 2003)	Focus Group Discussions, Key Informant Interviews with Religious Leaders
Caretaking practices	Gender norms related to caretaking, specific caretaking practices with a focus on practices with a high-risk of EVD transmission (e.g. caring for the sick)	Focus Group Discussions with women
Emic understanding of EVD messaging	Presentation of MoH approved EVD messages and FGD interpretation of the message, discussions around improved messaging and language (if applicable)	Focus Group Discussions with community members
Trust in health care workers	Community perceptions of health care workers, challenges encountered in interactions, accessibility of health care workers, uptake of health care workers' advice	Focus Group Discussions with community members
Livelihood practices	Current employment status (Yes/No) of participants, number of jobs and hours worked per week, consistency of employment and income, livelihood barriers or facilitators to health-seeking behavior and EVD preparedness	Focus Group Discussions with community members
Demographic Variables	Age and self-reported highest level of school completed; ethnicity, birthplace, employment status and type of work	Focus Group Discussions with community members; Key Informant Interviews
Community-level Category	**Operational Definition (Variables)**	**Data Collection Method**
Leadership practices and rapport	Leaders' work related to EVD preparedness, leaders' general work in the community, rapport with community members and uptake of leader advice (hypothesized differences along generational and gender lines)	Key Informant Interviews with local leaders, Focus Group Discussions with community members
Intra-community conflict	Local history related to conflict and destabilization along political or ethnic or other lines, which may impact trust of authority figures	Key Informant Interviews with local leaders
Social norms regarding safe burials	Indigenous burial practices from the moment of death, practices on washing and caring for the body, practices on burial and caretaking	Key Informant Interviews with religious leaders and health workers
Collective efficacy to prevent EVD	Perceived collective efficacy, shared belief among residents and community members, decision-making processes, capacity for achieving intended effect on EVD prevention	Focus Group Discussions with community members and Key Informant Interviews with all stakeholders
Social, cultural, and gender norms related to caretaking	Social, cultural, and gender norms related to caretaking, specific caretaking practices with a focus on practices with a high-risk of EVD transmission (e.g. caring for the sick)	Focus Group Discussions with community members and Key Informant Interviews with women's groups

Traditional healers' understanding of EVD transmission	Healers' emic perception of EVD etiology, disease transmission, causes of EVD, remedies or methods for preventing, controlling, and treating EVD, linkage (or not) to medical facilities and protocols for a suspected EVD case, emic explanatory models for EVD (see Hewlett & Amola, 2003)	Key Informant Interviews with traditional healers
Service Systems-level Category	**Operational Definition (Variables)**	**Data Collection Method**
Community trust & rapport	Working relationship with community members, areas of tension and areas of fluidity, uptake of advice and ability to influence community members' behavior	Key Informant Interviews with health workers and leaders
Incorporation of culturally-sensitive practices	Reliance on scientific methods and national policies/guidelines in work, incorporation of local cultural and religious beliefs, resolving the tension where applicable	Key Informant Interviews with health workers and leaders
Culturally-sensitive, safe burials	Points of leverage for changing unsafe burial practices, where applicable, and ideas/notions for improving unsafe burial practices, ideas on risk communication related to safe burial	Key Informant Interviews with local leaders, health workers and religious leaders

These variables were contextualized with data on the policy environment, including National Task Force coordination practices, national leadership & political will, state capacity and health systems, and relevant political, social & economic history. These contextual environmental data were also triangulated in Focus Group Discussions, Key Informant Interviews, and from Document Review and Observations.

2.4. Theoretical Frameworks

2.4.1. The Ecological Model and the Health-Belief Model

A more effective intervention would focus on the policy level so that a broad range of the population can be impacted, rather than simply focusing on the individual level. The **Ecological Model of Health Behavior** is a comprehensive and integrated model that considers the multiple levels of influence that affect an individual's health. The Ecological Model "emphasize[s] the environmental and policy contexts of behavior, while incorporating social and psychological influences" (Sallis, 2008, p. 465). In this section, we will examine the various levels of the Ecological Model, while arguing for an intervention grounded in the policy level.

The **Health-Belief Model (HBM) is on the intrapersonal level of Sallis' ecological model**, or the microsystem level, if using Bronfenbrenner as a reference (Wilson, 2011). The HBM

(Becker, 1974; Rosenstock, 1974) was initially developed to understand why people were or were not using preventative services that were offered by public health departments during a tuberculosis outbreak in the 1950s (Wilson, 2011). It is a static model that examines individuals' beliefs about whether they are at risk for a particular health problem (Wilson, 2011). In turn, these beliefs work together with a perceived benefit of actions that could help in avoiding disease, in order to influence an individual's willingness to act (Glanz, 2010, p. 402). Core constructs of the HBM include: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and finally, self-efficacy (Wilson, 2011). In other words, the HBM suggests that a person's actions relating to health are based on their beliefs about that disease or about health in general. More concretely, the HBM has been used to predict individual behavior as well as to design public health intervention programs that focus on behavior (Hounton, 2005, p. 2).

Sets of variables models, such as Rosenstock's Health Belief Model and social determinants of health, are useful for understanding health care utilization. The Health Belief Model grouped various factors into 'sets of variables,' including 'pre-disposing,' 'enabling,' 'need' and 'health care seeking.' Pre-disposing variables look at demographic factors such as gender and age that influence risk of illness. Enabling factors may examine the social network and environment to look at how this impacts illness, health and health-seeking behavior. 'Need' may examine the severity of the illness, and when an individual displays symptom of infection. Finally, variables that affect the decision to seek health care could include access, financial status, and more. 'Social determinants of health' is an important and vital sets of variables model; it is a multilevel analysis of the 'upstream' influences of health – including, political factors and governance, socioeconomic status, and other such factors of the broader sociocultural context (Vhalov et al., 2009).

Decision point models, such as Chrisman and Suchs models, include the cascade of decision-making factors that influence the final end-point decision of health care utilization. One such model uses categories such as "adopting the sick role in times of illness" (i.e. when a member of a household is allowed to reduce work productivity and take time to recover) to lay consultation (asking members of your network what to do in case of XYZ symptoms), the next decision to treat an illness if deemed serious enough (i.e. go talk to a doctor, if members of your network advise so) and finally, adherence (adhere to the protocol and prescription of the doctor).

One way to translate the HBM into a practical application is to develop HIV prevention programs that target other barriers of condom use. Hounton et. al. (2005) call for condom outreach programs at the community level (p. 6). Using their results as evidence, it is clear that programs which try to simply increase awareness of HIV/AIDS may not actually succeed or translate into increased condom usage. While a number of interventions can be designed based on this evidence, it would be prudent to design one that focuses on self-efficacy as a construct of the HBM. Self-efficacy can be defined as "a person's confidence in his or her ability to take action and to persist in that action despite obstacles or challenges" (Wilson, 2011). An intervention that uses the construct of self-efficacy could include social support groups that encourage women to speak openly about HIV/AIDS as well as condom use. This intervention could empower women to believe that they can and should insist on condom usage; that condoms are in fact effective in preventing the transmission of HIV/AIDS. This intervention would use peer support groups (a part of the microsystem), but it still would have an impact on individual behavior.

There are several strengths of designing an intervention that focuses on the microsystem level of the Ecological Model. Primarily, behavior plays a significant role in health and prevention. While we cannot overemphasize individual responsibility, it is often useful to design interventions that focus on behavior. In addition, there is strong evidence that behavior influences both morbidity and mortality (Wilson, 2011). Fisher (2011) argues that "environmental changes are achieved through their influences on behaviors" (p. 20). For example, if smoking is banned on a university campus, fewer people may smoke. Lastly, an intervention that targets this level is cost-effective and may be easier to implement (Fisher, 2011, p. 21).

Despite these strengths, single-level interventions are unlikely to be powerful or sustainable (Sallis, 2008, p. 479). Behavior change is only maximized when multi-level interventions are pursued. By changing the environment (macrosystem) that people live in, it is possible to support healthy choices. According to Cockerham (2005), the "individualistic paradigm" of health lifestyles fails to take structure (or environment) into account (p. 64). It places too much value on the ability of individuals to make healthy choices for themselves. The HBM is an individualistic paradigm that focuses on the microsystem and therefore does not

sufficiently consider environmental factors. It is of limited value to design an intervention that solely targets the microsystem level of the Ecological Model.

According to Bronfenbrenner, there are three levels of the Ecological Model: microsystem, exosystem, and macrosystem (Wilson, 2011). The *macrosystem* level includes history, culture, laws, social conditions as well as the economic system of a country (Wilson, 2011). An alternative health intervention could focus on the macrosystem level. A policy level intervention could be implemented that entails a government-led response to zoonotic disease outbreaks. The government should work together with civil society to promote an honest and open discussion about emerging infections. In this case for example, the government should implement information campaigns aimed at changing beliefs about Ebola. A campaign would promote how to protect oneself properly when caring for a loved one within the household early during appearance of suspicious symptoms as well as information that safe and dignified burial is, in fact, one effective protection against further transmission of Ebola.

There are a number of strengths associated with interventions that target the macrosystem level of the Ecological Model. By focusing on a larger scale, it is possible to make changes on an environmental level, so that individuals can make better decisions for their health behaviors. It is possible to reach entire populations rather than only those who choose to participate in individual level interventions. However, because changes at the policy level take place on such a large scale, interventions may lack specificity and are not easily measurable. It is difficult to test specific hypotheses, as there may not be a sufficient way to control for other variables when assessing the impact of a macrosystem change.

A key principle of the Ecological Model is that "multi-level interventions should be most effective in changing behavior" (Sallis, 2008, p. 466). According to this model, there are numerous influences that work together at various levels to influence individual health behavior. Therefore, if we are following the principles of the Ecological Model, it would be better to create an intervention that affects multiple levels. However, a macrosystem level approach (government policy) can do this by guiding mass media and policies of other community-level organizations and social groups that work at the microsystem or exosystem level. Therefore, it is recommended to pursue an intervention that is at the macrosystem level, as it will take advantage of the other levels of the ecological model.

2.4.2. Structural Violence

A concept of *structural violence* derives from a political economy approach, and was first outlined by Galtung (1990). It examines the kind of violence that results from unequal social structures that produce "unequal life chances" (Galtung, 1990; Rhodes et al., 2012, p. 208). Farmer (2004) outlines *structural violence* as the natural expression of political and economic exploitation and inequality. Farmer (2004) calls on anthropologists to document the complex workings of political and economic processes and bear witness to the harms that ensue by focusing on cost-effectiveness as an outcome. A key theme of *structural violence* is the role of *inequality*, or the differences in status based on gender, race, income, education, or typically, an intersection of these. Viruell-Fuentes, Miranda & Abdulrahim (2012) take an intersectional approach to immigrant health, arguing that structural factors pattern health outcomes among immigrants in the United States. These structural factors discriminate against individuals on the basis of social categories such as race and immigrant status, which intersect to produce poorer health outcomes (Viruell-Fuentes et al., 2012).

Inequality in income is strongly associated with inequality in health, which Farmer (2004) alludes to in his work in Haiti. How much inequality is necessary to underscore *structural violence?* How much inequality is, on the other hand, "natural" or acceptable? Would an equal, yet entirely impoverished society or nation not experience the violence that Galtung (1990) described? Also, there is sometimes a leveling of this discussion, with broader structural forces enacted on a local level, yet little is done to distinguish how these interact.

Central to a concept of structural violence is also the role of *power*, which Galtung (1990; see Rhodes et al., 2012, p. 208) cites as shaping unequal opportunities in life. In other words, *power,* is a bidirectional and invisible mortar that holds together the scaffolding of everyday life. One may have economic power (and not political), one may have rational-legal power (Weber, 1914; see Hanna & Kleinman, 2013), and so on. An individual both has some form of power and has power enacted upon them, in a mutually reinforcing and delicate balance. Here, it is the absence of said power in a social, political, economic, and historical context that shapes individual life and health. Rhodes et al. (2012, p. 223) also incorporate a concept of *structural vulnerability*, with *vulnerability* indexing location within a social structure that makes an individual more susceptible to the effects of social, historical, economic, and

political forces (or, structural violence). Structural vulnerability goes hand-in-hand with structural violence, and offers a helpful missing piece of theoretical frame.

Farmer (2004) and Farmer, Nizeye, & Keshavjee (2006) examine HIV/AIDS which lends well to analyses of structural violence. Farmer et al. (2006) argue that HIV/AIDS (and tuberculosis) require analyses of structural forces including racism and poverty. In other words, these are epidemics of opportunity, visible most in populations that have been affected by structural violence. Farmer's work does an excellent job of discussing the historical forces that have produced contemporary inequality. However, Fassin's comment to Farmer's (2004, p. 319) piece best captures the question of "how can ethnography apprehend this embodiment of the past?" How can we discuss contemporary inequalities and epidemics and clearly link them to colonial legacies? These linkages should, as Fassin points out, be made more explicit.

Two works examine structural violence in a context of maternal mortality. Mukherjee (2011) outlines the Millennium Development Goals (now, reincarnated as the Sustainable Development Goals) which seek to raise the status of women. However, as Mukherjee (2011, p. 594) points out, achievement of the MDGs must be located within an attention to broader determinants of health, including issues related to structural violence. The MDGs must be placed in context, as an extension of the neoliberal world order in which they were formed and articulated. Dunn (2014) similarly argues that policies are not translated into local change because they fail to consider the structural factors that shape maternal mortality.

Structural violence is less a theoretical frame and more a demonstration of the result of poverty. It is an effective political tool, with language that is passionate and action-inspiring. However, some definitions rely on injury and/or death as a result. Less visible are the everyday effects of *structural violence* that may not result in injury, but that nonetheless are equally impactful. Lee (2016) articulates Bourgois' (2001) work on political, symbolic, and quotidian, normalized violence. These less visible, less measurable forms of violence perhaps have the highest number of "victims" (although many would not self-identify this way). Moreover, as Rhodes et al. (2012) point out, *agency* is often absent in discussion of structural violence. Often, discussions of social structure are too focused on the big picture and do not allow room for individual actors within a social frame. Similarly, the role of *resistance* is also less visible in discourses of structural violence.

Part Three: Methodology

3.1. Introduction and Study design

This cross-sectional study employed anthropological research methods in order to describe the social and cultural context to inform EVD preparedness in high-risk districts in Uganda. This study relied on rapid ethnography - the use of focus group discussions, in-depth interviews, and participant observation - to answer the above-mentioned research questions.

3.2. Study Setting

This study was conducted in a representative subset of 17 districts in Uganda, which have been mapped into category one, at high-risk, and category two, at moderate-risk (Arua), for spread of EVD (MoH, 2018). Districts were grouped into five cultural groupings, namely: Bafumbira/Bakiga, Banyoro, Bakonzo/Batoro, Baganda and Lugbara/Alur; so that different cultural areas are sampled from to account for differences in the social and cultural context of EVD in Uganda and to capture a heterogeneity of settings. The table below illustrates the districts we visited.

Table 3. Study districts by cultural group

Cultural Group	District	Region
(1) Bafumbira & Bakiga/Banyakore	Isingiro	South-Western
	Kisoro	
(2) Banyoro	Kagadi	Western
	Buliisa	
	Hoima	
(3) Batoro & Bakonzo	Kabarole	North-Western
	Bunyangabu	
	Ntoroko	
	Bundibugyo	
	Kasese	
(4) Baganda	Luweero	Central
(5) Lugbara & Alur	Pakwach	Northern
	Arua	

The study was primarily conducted in district offices, health facilities (public hospitals, private clinics and pharmacies), daily-livelihood spaces (market areas, local shrines, water collection points, village meeting points) and at formal and informal border crossings. In each district, 4 research assistants worked to meet with the CAO and DHO to get the relevant approvals for research. All introduction and study approval letters were stamped by each districts' officials. From there, the team commenced work with an interview with the DHO or an official in the DHO's office. These interviews served as a guide to help us to hone our study sites in each district, while maintaining the interest in markets, landing sites, border towns, health facilities, and so on.

The table below demonstrates the specific locations where the study was carried out.

Table 4. Districts and specific locations for the study settings

District	Market name	Landing site, Lake	Border town	Parish	Sub County
	Bunagana		Bunagana TC		
Kisoro	Busanza		Busanza	Gitovu	Busanza
	Kihihi		Kihihi		
	Kashenyi				
Kanungu	Butogota				
	Bwambara				
Rukungiri	Rwenshama	Rwenshama, L. Edward			
	Ondramacaku		Ondramacaku	Anzu	Ayivuni
	Kampala		Kampala		Vurra
Arua	Vurra Customs				Vurra
	Panyimur		Panyimur	Boro	Dei
	Pakwach Main			Puvungu	Pakwach TC
Pakwach	Wadeli			Ojigu	Wadeli
	Lhubiriha	Kayanzi, L. Edward	Mpondwe Customs		Mpondwe Lhubiriha TC
Kasese	Kambukamabwe				
	Busunga		Busunga		Busunga TC
Bundibugyo					
Ntoroko	Kanara	Ntoroko, L. Albert	Ntoroko TC		Ntoroko TC
Hoima	Kaiso	Kaiso, L. Albert	Kaiso	Toonya	Buseruka
Kagadi	Muziizi	Kabukanga, L. Albert	Ndaiga	Kabukanga	Ndaiga

Specific attention was paid to district officials, health workers, market traders, customs officials, security personnel working at the borders, *boda boda* drivers, bushmeat hunters, and long-distance truck drivers as described below in the Methods.

3.3. Sample and Recruitment

The study population included community members (e.g. youth aged 15-24, men aged 25+, women aged 25+), religious leaders, traditional leaders and healers, community influencers/gate keepers, frontline health workers/responders to Ebola cases (e.g. Village

Health workers), local political leaders (e.g. Local Council I members), civil society members, Districts and National Task Force among others who live or work in five cultural groupings high-risk districts in Uganda.

"The main goal of our sampling was to focus on particular characteristics of a population that were of interest, based on potential involvement in the Ebola epidemic."

Study participants were selected employing non-probability sampling techniques as described below. These purposive sampling techniques relied on the judgement of the researcher in order to select a heterogeneous sample of individuals. The main goal of our sampling was to focus on particular characteristics of a population that were of interest, based on potential involvement in the Ebola epidemic. *Maximum variation sampling* is used here to capture a wide range of perspectives relating to Ebola. We selected units that exhibit a wide range of attributes, behaviors, experiences, qualities, situations, and so on. In other words, it was useful to gain greater insights into the Ebola phenomenon by looking at it from all angles. This also allows us to identify common themes that are evident across the sample and areas of disagreement.

Table 5. Phases of research and corresponding sample size by location

Research phase	Number of Participants	Number of Targeted Cultural Groupings	Total N
I. Document Review	----	----	----
II.a. Focus Group Discussions	10 per FGD	5 cultural groupings, 3 FGDs (youth, men, women) per grouping [Total 15 FGDs]	150
II.b. Key Informant Interviews	15	5 cultural groupings, 15 KIIs per grouping (religious leaders, local leaders, health workers, etc.)	75

Once the study team arrived in each of the above locations, we met with local council leaders or other officials (e.g. Customs Officials, Security Officers). The Local Council leaders and other officials served as guides and helped us to mobilize within each zone. The study team supplemented by engaging in "guided tours" of each area, which allowed us to become familiar with the specific study site, to observe any areas of cultural importance (e.g. traditional healers' homes), and to identify Ebola preparedness measures. For example, in Bunagana, two team members were taken around the town by a local volunteer who works

with women traders. We visited the border crossing site, crossed into 'No Man's Land'[5], participated in hand washing and other Ebola screening measures, spoke to *boda* drivers and other transport workers, visited markets, health facilities and private pharmacies, and spoke to countless residents of the area. This enabled us to gain a full picture of a border crossing point and identify specific challenges related to Ebola preparedness and control.

For the *Focus Group Discussions*, community members were purposively sampled based on cultural grouping and time spent in the community, with variable ages, gender, types of work, education levels, religion. Specifically, individuals who work in markets or hospitals and are more exposed to risk were recruited. Individuals who may qualify as a religious leader, traditional healer, local leader, etc. were streamlined in the Key Informant Interview phase. The preference for FGDs was to include community members with a variety of backgrounds.

Respondents for the *Key Informant Interviews* were purposively selected based on cultural grouping, type of job, role in the community (traditional healer, religious member, local leader, health worker, etc.), involvement in EVD preparedness, influence over matters related to EVD preparedness, and willingness to participate.

[5] Stretch of land between two countries' borders as conventionally designated by international law

The table below details the final number of participants for each cultural grouping.

Table 6. Final sample size (number of participants) by data collection and cultural group

Data Collection Phase	Cultural Group	Final Sample Size (N)	Number of FGDs
Focus Group Discussions	Bafumbira	40	4
	Banyoro	30	3
	Batoro & Bakonzo	57	6
	Baganda	38	4
	Lugbara & Alur	35	5
Total N	***-----***	***200***	***25***
Key Informant Interviews	Bafumbira	17	--
	Banyoro	15	--
	Batoro & Bakonzo	26	--
	Baganda	15	--
	Lugbara & Alur	14	--
Total N	***-----***	***87***	***--***

The cultural groups were classified based on different cultural traits existing between the five them including difference in languages (dialects) spoken, farming practices (staple foods grown) and socialization such as marital rituals. As such the social context may have some subtle differences that may affect EVD preparedness and response activities.

3.4. Data Collection

Data collection took place in March 2019 and included a cross-sectional study design, including the use of 1) document review, 2) focus group discussions, 3) key informant interviews, and 4) participant observation. Each method enabled us to form a full picture of the social and cultural context of EVD preparedness in Uganda. By engaging with multiple community members and stakeholders, we can better understand different levels of influence and their interactions related to EVD preparedness.

3.4.1. Document Review

Relevant documents were reviewed to support and corroborate the employed approaches. Document review included synthesizing all reports of ongoing activities by Ministry of

Health, district health officials, implementing partners, and reports compiled by the National Task Force. Literature review involved reviewing both grey literature and published books, journal articles and reports. Reports and published literature were synthesized to map the ongoing social science efforts on EVD in Uganda. Document review supplemented, validated and confirmed the information gathered from field investigations and will inform the social and cultural context of EVD preparedness. Further, we have taken care to engage in discussions with National Task Force and MoH stakeholders where areas of clarity are needed, or if documents are not up-to-date due to the rapidly evolving nature of the EVD preparedness work.

3.4.2. Focus Group Discussions (FGDs, II.a.)

Focus Group Discussions (N=25) were conducted with community members (N=200). Preference for this data collection method was influenced by the desire to capture as many diverse views from different people within the shortest time possible and also the tendency that most people can comfortably discuss sensitive topics in a group rather than through individual interviews. Each FGD was held in an appropriate and private place and had a moderator; female gender groups had a moderator of the same sex. A note taker was noting during the discussion but nevertheless, a digital recorder was used in order to ensure verbatim recording and reduce the risk of data loss. An FGD guide was used by the moderator in order to keep on track of discussion topics.

In the FGD, the interview guide was tailored to the type of FG participant, but covered topics such as religious & safe burial practices, caretaking practices, trust in health care workers, livelihood practices, leadership practices and rapport, collective efficacy to prevent EVD, social, cultural, and gender norms. See the Appendix for this guide.

3.4.3. Key informant interviews (KIIs, II.b.)

Key informant interviews (N=87) were conducted with different stakeholders within the community including those who might be directly and indirectly involved in EVD response. These included religious leaders, traditional healers, local government and business leaders, health care workers, formal women groups' leaders, and security/uniformed personnel. Twenty-five of the key informants were women. All key informants were adults aged above

18 years. Interviews (roughly one hour per interview) were conducted by the research team in the local language or in English, depending on the *lingua franca*. The interviews covered a range of topics including: religious beliefs & safe burial practices, leadership practices & rapport, intra-community conflict, social norms regarding safe burials, collective efficacy to prevent EVD, social, cultural, and gender norms related to caretaking, traditional healers' understanding of EVD transmission, community trust & rapport, and incorporation of culturally-sensitive practices. See the Appendix for this guide.

3.4.4. Participant Observation

Participant observation was conducted in order to provide more detail and context related information about the EVD preparedness and response activities. It permitted collection of information on facts not mentioned in interviews conducted above (Bernard, 2011). Participant observation involved the research team actively participating in activities undertaken during the preparedness processes for responding to EVD. Researchers attended stakeholder meetings for the National Task Force and coordination meetings at field sites/districts and also meetings for Ministry of Health implementing partners. This observation informed the ways in which EVD preparedness efforts are perceived by community members. Moreover, the research team observed activities such as market days, border crossings, festivities, local work on EVD preparedness and response, leadership and coordination meetings, cultural & religious ceremonies, health worker outreaches, and other relevant public meetings or interactions. The research team participated in border preparedness activities, such as hand washing, temperature screening, and cleaning shoes in bleach. We also noted the readiness of isolation tents and other measures in case of any suspected case. Together, this observation informs the social and cultural context of EVD preparedness. See the Appendix for this guide.

3.5. Data Analysis

Qualitative data analysis employed an inductive and emergent approach as follows, typical in a thematic analysis approach (Bernard, 2011). Field notes were written immediately after completing each interview to document the interview content and process. We used these contextual data and the guiding research questions to devise a codebook that captured the various themes throughout the

Our analysis relied on thematic analysis to identify categories and themes that inform the social and cultural context of EVD preparedness.

research process. We also held a final de-briefing meeting with all research assistants in order to cross-check findings and to compare themes across regions. Then, transcripts were read through so that the researchers were familiar with the data. Then, themes were identified and related categories were sourced out. For each category, we identified a number of codes. Each code serves as an indexing or measurement device to assign values to the text and help organize the data. After the codebook was developed, we pilot tested it on five KII transcripts and two FGD transcripts from various cultural groupings. The codebook was then refined to address any areas that lacked clarity. An extract of the final codebook is shown in the annex 7. During the analysis phase, topical and thematic codes were applied to the transcripts and field notes. The coding process was iterative and ongoing and used *a priori* codes chosen beforehand (see the codebook) and *in vivo* codes that come up throughout the analysis (Bernard, 2011; Schensul et al., 1999). Memo-writing was an important part of the analysis to aid in the exploration of the data and to keep a record of thoughts and the analysis process. Codes were synthesized into categories and themes, while variables were compared across levels of analysis.

By analyzing data in a grounded manner, we were able to describe the social context of EVD in Uganda, and community perceptions and behaviors that can impact EVD preparedness and response. Further, we were able to understand the relationship between community members and stakeholders for better EVD preparedness. Finally, we will create explanatory models (see Hewlett & Amola 2003 for their work in Northern Uganda) for each cultural grouping based on these analyses to describe the cultural context of EVD in high-risk districts. These explanatory models will be disseminated via shorter briefs.

Information gathered during the document review informs the social, cultural, political, historical, and economic context of our findings. We conducted a content analysis of documents gathered and created an online Dropbox folder that can be easily and quickly disseminated to stakeholders. A content analysis is a technique for the objective, systematic, and quantitative description of the manifest content of communication (Berelson, 1952). The content analysis (Berelson, 1952) allows us to quantify and analyze the presence, meanings and relationships of certain words, themes, or concepts. We then could make inferences about the messages within the texts, the writer(s), the audience, and the culture surrounding the text. The texts were coded and then codes were further categorized into themes to allow cross-comparability and integration across methods (FGDs, KIIs, and document review).

3.6. Training of Research Assistants

Twenty research assistants were recruited for the study, with care taken to choose 3-4 research assistants for each cultural grouping. Each team consisted of 2 females and 2 males, who had comprehensive knowledge of the language and cultural practices of each study site. The research assistants had experience in qualitative and anthropological data collection and experience in conducting fieldwork with vulnerable and other population groups.

To ensure a high level of data collection, the research assistants recruited for the study received comprehensive training prior to the data collection. The training took place in February 2019 (see Appendix 6 for the agenda and topics).

3.7. Ethical Considerations

Approval was obtained from the Uganda National Council for Science and Technology (SS 4910) and Makerere University School of Social Sciences Research Ethics Committee (MAKSS REC 01.19.252) to ensure adherence to research protocols, procedures, and ethics, and human subjects protection (See the Appendix). The study was also registered by the Office of the President, Research (See Appendix). Informed consent was sought from all participants including community members, key informants from the districts and national level respondents by asking them to sign informed consent forms if they accept to take part in the study. All other issues pertaining to social research including respect for participant dignity and freedom of participation, objectivity in reporting, privacy, anonymity and confidentiality in handling data will be necessary. In designing the tools for example, the consultant ensured that no identifiable information links the data to the specific respondent by using nominal identifiers such as numbers or pseudonyms rather than individual's actual names. Psychological and legal harm will be avoided by all means by the research team. Participants hold the right to choose what information they want to reveal or not. Privacy was insured by conducting focus group discussions and key informant interviews in private places in light of the sensitivity of the matter being investigated in the study.

3.8. Risks and Benefits

There were no major risks to participating in this study. As this research included only observation and interviews that do not ask about personal information, it was considered minimal risk. However, the researchers were sensitive to any negative psychological responses and emphasized that the participant had the option to discontinue the interviews or focus groups at any time. If the participant exhibited discomfort, the researchers had planned to refer the participant for counseling and psychosocial support from a trained service provider. Researchers were trained to handle such cases and identify both physical and psychological signs of discomfort. Notably, none of these situations arose. This research informed the context of EVD preparedness in Uganda and this information on detailed cultural contexts in high-risk districts was necessary to informing EVD preparedness.

3.9. Data Management

3.9.1. Data Storage and Management

All paper documents, including marked interview schedules, interviews and focus group discussions, and field notes, were scanned as .pdf documents for electronic backup purposes. Additionally, any handwritten paper documents were transcribed using Microsoft Word. Photocopies of paper archival sources were also saved as .pdf files. All audio files were saved as .mp3 files. No specimens or records were gathered or used in this study. Some of the data was sensitive in nature.

Data was shared with the PI on this project and with members of the PI's analysis team. Research assistants were present for some of the participant observation and for the interviews. The research assistants had social science training and are human subjects certified to understand confidentiality and the need to keep all information private. Also, all members of the study team completed the WHO's Ebola Training Certificate. In addition, the researcher reviewed appropriate study aims and procedures with the research assistant, including confidentiality and privacy, prior to beginning the interviews. The research team and UNICEF have sole access to the interview tapes, and the research assistants transcribed the audio recordings, in Microsoft Word. Further, quality was assured by the analysis team,

who entered and verified all data, developed the codebook, and coded under the supervision of the PI.

When the write-up is concluded in May 2019, the notebook containing contact information will be destroyed. The consent forms will also be retained in a locked file cabinet until the study is closed out with the MAKSS REC. De-identified data, including recordings, will be kept on a private, secured laptop in perpetuity and hand-written notes will be kept in a locked private room.

3.9.2. Data Format and Future Storage

All study data will be retained indefinitely. Hard copies of transcripts and field notes, in de-identified form, will be archived in a research office in locked file cabinets accessible only to the PI and UNICEF. All of the electronic data are stored on a 32-bit encrypted, password protected external hard drive and computer. The researchers developed the data codebook, de-identified all of the data, and retained the master list. All paper data were stored in a locked box while in the field and in locked filing cabinet while at Makerere University as is standard within the discipline.

Part Four: Findings of the Study

4.1. Findings Overview

This report details the social, cultural, and behavioral factors associated with the EVD outbreak with implications for risk communication and social mobilization activities and Ebola preparedness in Uganda. The findings are divided into the following sections:

- *Livelihoods and health*. How community's and individuals' livelihoods impact their ability to seek health care, with implications for Ebola preparedness.
- *Religious and traditional beliefs*. How religious (Muslim, Christian) and traditional (by cultural grouping) beliefs impact health-seeking behavior, including when to seek assistance from a traditional healer rather than from the formal health sector.
- *Burial practices and funeral rituals.* How burial practices are an integral part of cultural beliefs in each area studied and how these practices may shift or not shift given Ebola risk.
- *Caretaking practices.* The ways in which community and gender norms shape who takes care of who and how during times of illness. This was an important theme that emerged in other patriarchal societies, where the burden of care falls to women and therefore women are more vulnerable to Ebola.
- *Health beliefs and health-seeking behavior*. How cultural and social beliefs shape decision-making around health and how this is also impacted by access or distance to health facilities.
- *Trust between the communities and authority.* The social and cultural context of trust between communities and authorities such as health workers, local leaders, and so on, with implications for Ebola preparedness.
- *Social, Political, and Economic Context.* How the broader context shapes community's ways of coping with disadvantage and vulnerability, with implications for Ebola.

Possible areas of fear, concerns and other negative reactions to information and practices related to EVD prevention are highlighted, as are specific points of leverage (e.g. community/cultural assets) that can be used to support EVD preparedness.

4.2. Policy Review

This section reviews key policies and documents, especially in the grey literature, that are related to Ebola preparedness in Uganda. These documents have been synthesized into a shareable Dropbox and Google drive folder which can easily be disseminated to stakeholders.

The Ugandan Ministry of Health's *National Ebola Virus Disease Contingency Plan* (Oct 2018-Mar 2019) aims "to enhance Uganda's capacity to prevent, detect early, and effectively respond to Ebola Virus Disease spread from Democratic Republic of Congo (DRC) to Uganda." It highlights the risk of Uganda for importing Ebola via its close and shared borders with the DRC. According to the plan, EVD preparedness should include a scale up of risk communication in partnership with village health teams and Red Cross staff, the situating of Ebola Treatment Units (ETUs) closer to the affected or high-risk communities, and the training of additional teams for safe and dignified burials in each high-risk district. Specific objectives of the plan include the following:

Figure 7. Objectives of Uganda's Ebola Contingency Plan (MoH, 2018-2019)

General objective

To enhance Uganda's capacity to prevent, detect early, and effectively respond to Ebola Virus Disease spread from DRC to Uganda.

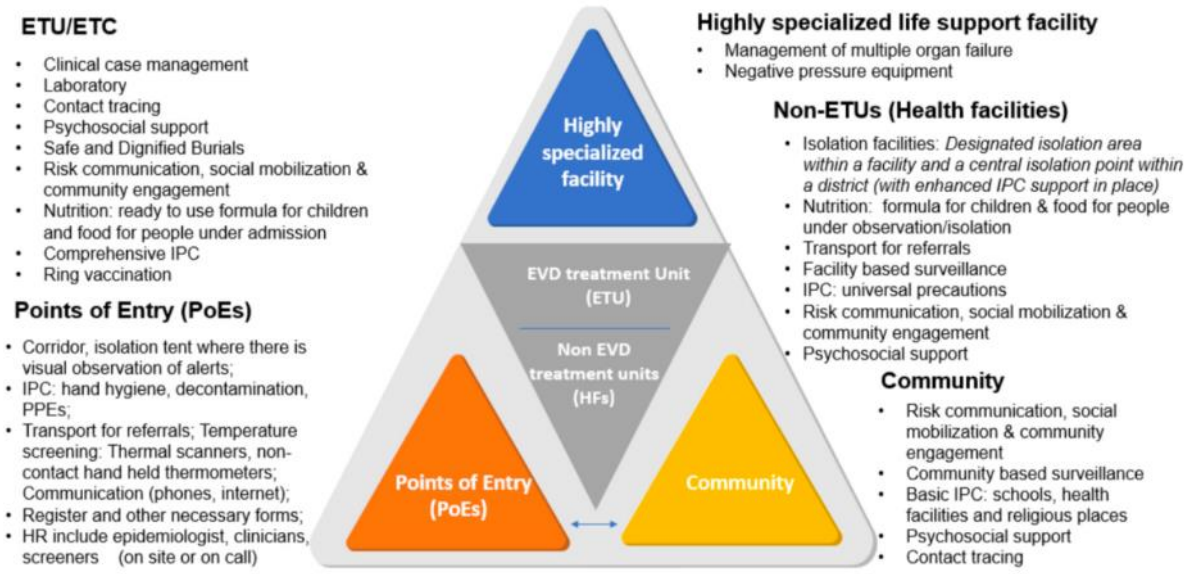
Specific objectives

The specific objectives are to:

- Mobilize partners and resources for effective EVD preparedness and response.
- Enhance district capacity to prevent, rapidly detect and investigate all suspect EVD cases in elevated risk districts.
- Raise public awareness on the threat of EVD and galvanize community support for prevention.
- Build capacity for EVD case management and response in elevated risk districts.
- Strengthen capacity for basic infection prevention and control in primary health care facilities in elevated risk districts.
- Build the capacity for the deployment offend vaccination and investigational therapeutics.

Since the plan was written, Uganda has since had an outbreak with three confirmed cases of Ebola (MOH, 2019). Actions recommended include a multisectoral response at the community level, at points of entry, at health facilities, and the establishment of ETUs as needed. The plan calls for preparedness in case of a mass flow of refugees, whereby "thermal scanners will be deployed at the border points when the arrival rate reaches at least 1000/day." Additionally, the plan calls for a minimum package for EVD preparedness and response, as displayed below:

Figure 8. Minimum package for EVD integrated preparedness and response (MoH, 2018-2019)



Specific plans and objectives are outlined in the document for each of the above-mentioned activities.

The World Health Organisation and partners (2018) have outlined its principles of risk communication and community engagement in two key documents: 1) *Risk Communication and Community Engagement (RCCE) Considerations: Ebola Response in the Democratic Republic of Congo* and 2) *Risk Communication and Community Engagement Preparedness and Readiness Framework: Ebola Response in the Democratic Republic of Congo in North Kivu.* Risk communication and community engagement are key for any disease outbreak response, but particularly critical during Ebola outbreaks which are mired by instability, rumors, and mistrust. It helps to transform complex scientific knowledge into actionable steps that community members can take for surveillance, case reporting, contact tracing, and so on.

UNICEF's Communication for Development (C4D) strategy seeks to share relevant and action-oriented information so that stakeholders know what actions to take on Ebola preparedness and control. C4D is especially necessary in the Ebola crisis as it helps to shift cultural practices that may put people at risk of Ebola. The only way to do this sustainably is to use risk communication and social mobilization tactics to enable communities to protect themselves, care for the sick, and safely bury the dead. *Risk communication* understands that

threats to outbreaks require a rapid dissemination of timely, correct, and consistent information to the public. It should ideally take into account both Under C4D, *social mobilization* also plays a vital role in the Ebola response by building on community strengths to improve uptake of Ebola prevention messages and control.

4.3. Livelihoods & Health

This section details the ways in which community and individual livelihoods shape Ebola preparedness, prevention, and response. In this context, livelihoods refer to economic modes of subsistence including market trading, cash crop agriculture, fishing, transportation, or small businesses. Wherever our team went, we listened to communities tell us that although they might be afraid of Ebola, they cannot change the way that they are behaving due to economic constraints. In other words, although long-distance truck drivers in Vurra are afraid of Ebola, they still have to cross deep into DRC in order to do their work. *Boda boda* riders still carry dead bodies from the DRC, despite knowing the risks, because they have to earn a living and cannot refuse the money that such work pays. Many described a limited capacity to change their behavior in light of their economic needs. Livelihood strategies among our participants ranged, from fishermen to farmers, from long-distance truck drivers to *boda boda* riders. We interviewed health workers (*n*=44), traditional healers (*n*=6), local leaders (*n*=14), religious leaders (*n*=10), teachers (*n*=4), and students (*n*=30) across all districts. Despite these differences, we noted that participants were struggling to make ends meet and therefore had limited capacity to make behavior changes such as taking a sick child to the hospital or limit movement into the DRC during the epidemic.

Constrained agency

In Kisoro District, in Southwestern Uganda, the team noted that there was a high level of knowledge about Ebola - its origins, prevention, and treatment. Overall, people in all areas had a high level of fear of Ebola. Yet, their ability or efficacy to change behaviors was weighed against the need to continue regular socioeconomic activities, much of which is subsistence work. For example, in Bunagana - a town at the border of Uganda and the DRC, traders regularly cross the border to engage in market trading, to obtain cheaper goods and

> *"Another problem is lack of better health facility. Bunagana is supposed to have a better health facility. We only have a small health center which is not in position to cover various complicated diseases. Like mothers cannot be helped at time of giving birth. And other complicated cases are referred to Kisoro hospital. And you see from here to Kisoro is a long distance. So it is our need for our health facility to be improved."*
>
> ***Location of the interview:*** *Kisoro district, Bunagana at Uganda-DRC border*
> ***Designation/ position:*** *Religious Leader Muslim*

items. Furthermore, due to a lack of reliable water on the Ugandan side, many Ugandans cross into DRC to fetch water.

Cross-border movement and livelihoods

The study noted a high level of regional connectivity, with large numbers of people crossing the border each day. We noted mainly circular movements - Congolese come to Uganda to purchase merchandise, for school or health care services, then return to the DRC shortly thereafter, and Ugandans go into the DRC for water or to trade at the market, and then come back shortly thereafter. As one official noted, the populations inter-marry, inter-trade, and inter-socialize. Quite a few Ugandans even go into DRC to cultivate land and grow crops, where there is reportedly richer soil. In other words, there is a high level of cross-border movement and socializing. This presents a major challenge to Ebola preparedness. Those traders who engage in illicit activities (such as smuggling cigarettes and locally manufactured alcoholic brew) and want to avoid customs officials will cross at informal border crossing points. Others, who may want to avoid the bureaucracy of crossing a border, also use the informal border crossing points. More must be done to prevent the spread of Ebola across those particularly vulnerable informal border crossings.

A border town, Bunagana, Kisoro District

A market in Bunagana, at the border of DRC-Uganda in which both Ugandans and Congolese sell side by side

Vectors of disease & Ebola stigma

Moreover, the vectors of Ebola were often identified as Congolese individuals, as most responses focused on limiting contact with Congolese. No attention or worry was paid to others (e.g. Ugandans) who had crossed into Ebola-affected DRC. For example, one individual spoke about a man who travels to DRC and focuses on the man's contact with Congolese as a risk factor for Ebola:

> *"...when he comes back, he will not come when everyone is seeing him. He will sell his fish from there then comes from the bush and enters the house yet they teach us that **anybody who gets in touch with Congolese**, should wash hands when he comes back because they told us that Ebola came from Congo so he will not get a chance to go and wash hands. And in many cases many people have died from the park, he goes there, gets in contact with Congolese and when he comes, he just enters the house, then you hear that so and so died without even going to the Hospital."*
>
> ***Location of the interview:** Rweshama Landing Site, Rukungiri District*
> ***Designation/ position:** Community Member - Female*

Animal interactions & Ebola

Another key factor related to livelihoods is the ways in which people interact with animal vectors. Men (*n*=9) at an informal border crossing near Vurra in Arua District described their love of hunting bushmeat. All men in the FGD agreed that hunting in that rural area was a

key modality of sustenance. When asked what their favorite kinds of bushmeat were, they responded "monkey." Monkeys are caught in the forests in this rural area straddling DRC and Uganda. They are butchered by the men and cooked by the women - usually served alongside roasted cassava. When later asked about ways in which Ebola spread, the men knew that bushmeat was one way that Ebola spreads. Yet, monkey is a key source of protein that is required for survival as other meat is too expensive and often unavailable. This sentiment was echoed across the study area/other cultural groups. In Rukungiri District, the concern was more related to interactions with bats – and while these may not be the actual bats that are thought to be EVD reservoirs, bats infest community members' homes and people find it hard to avoid contact with them.

Urban versus rural areas

Location was also a key factor that shaped health-seeking behavior with implication for Ebola preparedness and control. While vulnerable people live both in towns and in villages, rural areas of the border districts are particularly disadvantaged and underserved by health facilities. In one interview, a Disease Surveillance Officer in Hoima district, which lies along Lake Albert where heavy cross border activities occur, described the challenges in reaching rural populations in his catchment area including bad roads and long distances. These statements are mirrored in community member interviews, whereby individuals prefer to seek care from local private facilities or traditional healers, rather than traveling far to government health facilities.

"I think last week we were with a team from UNICEF, we went to one of the landing sites in Kibero parish and we discovered that in the market place; these women who are selling fish and flour know about Ebola. So, we asked where they got information and they said it was from church, lay readers and pastors, from the burial place, the chairman LCI and the VHTs talk to us. Others said they get information from facilities; health centers and others get it from the radio. ***Of course, there are deep populations along the landing site that we can't access****."*

Location of the interview: *Hoima District*
Designation/ position: *Disease Surveillance Officer*

Conclusions

Overall, it was noted that although the level of awareness and fear of Ebola is high, many people could not suspend their daily economic activities or were unable to reach health facilities during times of illness. Due to the economic vulnerability of communities around

the border, the perceived risk of Ebola was not as high as the potential loss of income that might result from staying in place and not going to DRC. The team noted that this would certainly change were there an active case of Ebola in Bunagana or the nearby areas. As of now, Ebola remains a "remote" or "unclear" threat, and many people are not as concerned or are not able to change their behavior to prevent it. When they are concerned, they focus on Congolese individuals as vectors of disease, which has perhaps fueled a sense of stigma and discrimination against Congolese populations coming into Uganda. These findings have implication for risk communication, which should consider the ways in which individuals' livelihoods shape their capacity to make behavior changes.

Modes of transportation & carrying of goods across borders.

Top left: a *boda boda* rider
Top right: a long-distance truck
Left: a *takisi*

The major challenges to EVD preparedness in high-risk districts are two-fold: 1) livelihood practices, and 2) perception of EVD risk. In many border areas, respondents discussed the fact that they had not seen an actual case of Ebola and therefore their perception of their risk was somehow low. This was contradicted by the high level of overall fear of Ebola. One explanation for this paradox is that despite fearing Ebola, many people must continue with their daily activities that take them across the border or facilitate interactions with people who come from the DRC. This represents the issue of livelihoods. If there is better economic opportunity across the border in DRC, market traders and other businessmen will cross into Congo regularly. It is unlikely that this practice will be stopped, even when there is an active

case of Ebola on the Ugandan side of the border. Indeed the recent outbreak of ebola in Uganda is partly attributed to the need for the index cases to return to Uganda to continue with their livelihood. The index cases were members of a family married into Uganda and thus needed to return ‘at all costs’ to their Uganda-based family. This "Ebola complacency" as we can call it, represents a major challenge to EVD preparedness work.

4.4. Religious and Traditional Beliefs

This section details religious and traditional beliefs in the various cultural groupings, with implication for Ebola preparedness, prevention, and control. Religious and traditional beliefs varied by cultural grouping across all districts. Often, individuals ascribe to different beliefs and practice a dualistic model of religion belief. Namely, individuals report to be Catholic or Muslim, while also practicing their own local traditional faith. While these individuals might go to church weekly, a traditional healer or spiritualist is sought for issues related to family, clan, or spirits. Indeed some traditional healers also subscribed to other religious beliefs simultaneously as evidenced by their healing venues and setting. This might seem paradoxical, but individuals are able to reconcile their differing belief systems and practices. Any explanatory model of religion and tradition in Uganda must consider both of these belief systems.

Culturally, due to the high rate of inter-marriage between Congolese and Ugandans, many individuals at the border have family across the border. When they meet those family members, they greet them with a hug or a kiss - representing a possibility of Ebola transmission.

4.4.1. Religious Beliefs and Ebola

All of the major religions were represented in our sample, with interviews conducted with imams, sheikhs, pastors, and other clergy. Key informants from religious groups (n=10) demonstrated a high level of knowledge about Ebola - its origins, how to control for it, and what to do in case of a suspected case. At times, these beliefs were alongside traditional spiritual beliefs as well - mixing the scientific with the spiritual. For example, one Imam discussed the use of both Western medicine and spiritual healing side by side:

*"A number of times there are people who are affected by demons but as Muslims we have verses that **pray for them and we encourage them to take medicine** as we pray for them, usually we encourage using government medicine to heal people as we pray for them."*

Location of the interview: *Kihihi Town Council, Kanungu District*
Designation/ position: *Imam, Kihihi Mosque*

Other Muslim beliefs have positive implications for Ebola prevention, especially with regard to touching. However, the beliefs are specific to touching individuals of the opposite sex and not specific to touching individuals of the same sex (e.g. hand shaking, etc.).

"It's not Ebola only, Islam teaches people to keep safe from any disease, Islam says that any woman who's not your mother or sister should not be touched in their hands, instead of touching that woman, allow them to nail a 6 inch nail into your head but don't touch her hands, as a safeguard to avoid you contraction Aids, syphilis through continuous interaction with foreign women. The diseases like Ebola and the rest also come from such situations that may make one spread to others hence Islam teaches like that."

Location of the interview: *Kihihi Town Council, Kanungu District*
Designation/ position: *Imam, Kihihi Mosque*

The same Imam in Kanungu District continued on the theme of touching and advice for Ebola prevention. For example, he counsels his followers to wash their hands, especially for those traders who cross into DRC. This is a good example of how religious leaders are engaging their followers for better public health outcomes:

*"We are taught about that, and that is why you see that **Islam does not allow you to touch anyone in their hands.** You are not supposed to touch the blood or urine from that person. In case he sweats which is a sign of Ebola; you are not supposed to be touching him. So, we are going to Congo most especially traders, we advise them to wash their hands, there is medicine that was put there by the government and wash their hands when they are living Congo, they teach him how to wash his hands so for that one people learnt it. So, people learnt that because prevent is better than cure."*

Location of the interview: *Kihihi Town Council, Kanungu District*
Designation/ position: *Imam, Kihihi Mosque*

Women at Rwenshama Landing Site described Muslim beliefs around drinking and how it affects Ebola. The community member describes how Muslims are not supposed to take

alcohol, but she was in the bar drinking that day. It is unclear whether the cases she is referring to were actual cases of Ebola or just suspected cases of Ebola:

> *"...what someone told me, he came and told us that I was in Bundibugyo, she said that the medicine of Ebola is Waragi (Alcohol), that, that side many people got Ebola but* ***we who had stayed in bars the whole day drinking we never got Ebola*** *she continued that even when doctors came they looked for us who were drinking and we were the ones to help the health workers, you would be drunk but you would be the one to carry the Ebola victims. And we asked that now for us who are Muslims can we start taking Alcohol so they were puzzled how we were going to avoid Ebola."*
>
> ***Location of the interview:*** *Rwenshama Landing Site, Rukungiri District*
> ***Designation/ position:*** *Community member - female*

Christian religious leaders similarly described a higher level of knowledge about Ebola. Religious leaders interviewed in this study described advising their community to wash hands, with one religious leader in Arua describing that: "*the religious leaders mostly at churches do tell people where Ebola comes from, how dangerous it is and how to avoid / prevent getting Ebola virus*." Religious leaders report telling their communities to refer any suspected cases to health workers, demonstrating that churches and mosques are an excellent way of disseminating Ebola information. Moreover, a precedent has been set where engaging religious leaders went a long way to significantly improve uptake of public health interventions that require behavior changes in cultural practices (Sewankambo and Mafigiri, 2017).

4.4.2. Traditional Beliefs and Ebola

The category of 'traditional healer' captures a variety of typologies in Uganda. An *herbalist*, for example (e.g. an "o*musawo omuganda"* in Luganda) works strictly with local plants to cure illness. Individuals often seek care from an *herbalist* for medical issues such as malaria, fever, diarrhea, etc. An herbalist relies on centuries of local knowledge about plants that can be used to heal such diseases. For example, aloe plants are commonly used and made into an infusion to treat fever or diarrhea. Typically, trust in herbalists is quite high, compared to health workers. In rural areas, where health facilities are far away or non-existent, an herbalist is the first and only point of contact with a health provider.

A *spiritual healer* or a *witch doctor* (*"omusamizze"* in Luganda), works primarily with spirits and ancestors. Individuals often seek care from a *spiritual healer* for family issues, family conflict, or for personal issues such as mental illness (often perceived as a disturbance by a spirit). In these cases, ritual sacrifice may be necessary. The family may need to come together with the *spiritual healer*, sacrifice a goat or other animal, and then eat together along with a series of rituals to the spirits. Herbs and plants may also be used, but these healers are primarily dealing with spiritual issues. The different categories and local names are detailed below by cultural grouping:

A Baganda *omusamizze* house usually with drums, shields, spears, bark-cloth, animal skins and gourds

Table 7. Cultural groups, traditional healers, and local names

Cultural Grouping	**English Name**	**Local Name**
Baganda	Herbalist	*Omusawo omuganda*
	Spiritualist/witch doctor	*Omusamizze* *Omulaguzi* *Omulogo*
Batoro	Traditional healer	*Omufumu*
Bakonzo	Traditional healer	*Abathahwa abekyiyira*
Banyoro	Herbalist	*Omufumu*
	Spiritualist/witch doctor	*Omurogo*
Bafumbira	Herbalist	*Umuchunyi*
	Spiritualist/witch doctor	*Umuftumu* *Umuraguzi*

Traditional healers are often well-respected and sought-after individuals, particularly in communities where health facilities may be hard to reach or health workers are not trusted. In Kisoro District, one traditional healer described his work in Bunagana, a border town with

two private health clinics and one hard-to-reach Health Facility II. This traditional healer treated every sickness, from epilepsy, to diseases of a spiritual nature. Further, while traditional and religious beliefs may be followed by the same individual, traditional and religious leaders do not always get along.

"We are still finding out as Ebola is a very new disease and we believe God will help us in this search. Many people look at us and call us witch doctors, but we are not. We use natural grasses/herbs, even pharmacists use them as well. Some religious people rebuke us for nothing."

Location of the interview: *Bunagana Border Town, Kisoro District*
Designation/ position: *Traditional Healer*

Despite these tensions with formal health facilities and religious leaders, traditional healers are also playing an important part in advising the community on Ebola prevention. Traditional healers in this study described advising their communities to use the screening and hand washing facilities, where available, and to report cases of Ebola immediately. One traditional healer in Luweero, who also describes himself as a Muslim talked about the barriers to seeking care in a hospital and what he would do in the event of a suspected Ebola case:

A traditional healer's toolkit, Kisoro District. Presence of local herbs, shields, animal skins, borns and gourds alongside posters bearing Christian symbols and biomedical anatomy is illustrative of a syncretic approach to healing. Such a healer would be accommodative of any one regardless their major conviction, hence their appeal.

"It's financial crisis, someone can be there suffering from malaria and going to the hospital it necessitates that person having some money and he does not have the money when he goes and gets for example 1000/= he will not be able to get transport that brings him to the hospital so let me just buy Panadol so that I feel relieved in most cases what limits people its financial crisis...others its financial crisis when one is unable like incase when I got to a private hospital and am admitted and ***then they ask me for 200,000/= yet I don't even have 10,000/=.***

As we saw that Ebola is transmitted in different ways that is eating dirty things, in such conditions this Ebola can be contracted, we have to take caution of the hygiene, taking medicine, something that calls for working together, getting trainings on how we can prevent the Ebola disease...if the Lord guides us ***we cooperate as doctors*** *because we are all doctors and trying to fight for their lives...because every person or every hospital there are things they know, that we might do not know, to me in relation to the traditions its then too much."*

It is also important to note that while traditional healers are very important to engage, it is not always easy. This is specifically due to their conflicts with trained health workers and other security organs, who might regulate their work. In Arua District, traditional healers were called to a recent training on Ebola. Due to their conflict with the formal health system, only 32 showed up at the training. Many others were afraid that this training would be used as an opportunity to arrest traditional healers, who operate in a legal grey area. Much more needs to be done to engage traditional healers, particularly in rural areas where these individuals are the first point of care. One possible point of entry to engage traditional healers is through their associations. In most regions of the country including the study area, traditional healers have associations through which they advocate for their rights and support each other.

4.5. Burial Practices and Funerary Rituals

This section discusses burial practices and funerary rituals, with implication for Ebola preparedness and control. In all districts where we sampled, burial rituals are incredibly important and a vital aspect of local culture. Rituals include similarities, where bodies must be returned to the ancestral land - on the father's side, where land is owned. Land ownership and paternity is intertwined with a sense of identity - both in life and in death. Bodies are kept at home, and people spend the night with the body, keeping watch over the body and its soul. Then, the body is prepared for burial - it is washed, cleansed, rituals are performed, and the burial takes place. However, communities will go to great lengths to ensure that the body's soul is at peace. Oftentimes, this might involve unusual transportation methods (like sitting the dead body on a *boda boda* motorcycle taxi in an upright position to disguise the fact that they are not alive) or dodging health workers. Any safe burial practice must consider local practices, norms, and beliefs. This section details cultural norms beginning with the transportation of dead bodies, washing of dead bodies, and onto other rituals.

In Kasese, Luwero, and Arua Districts, our team heard stories of *boda boda* drivers transporting dead bodies across international and district boundaries. This is a point of serious concern. More often than not, individuals cannot afford to transport a dead body in a car or other vehicle and *boda bodas* are a convenient and affordable option. In Arua, the process was described in detail. A local wicker chair is tied onto a *boda* and then the dead body is put on that chair. The body is tied to the chair and transported, sometimes for very long distances. When asked how they get across international borders (e.g. DRC-Uganda), individuals replied that "they give something to the military checkpoint people" and then are easily able to proceed onward. If an individual is not buried on their ancestral land, the person's spirit will be uneasy and unable to rest. That spirit will disturb living family members.

Responses about burial practices differed greatly from community members to religious leaders. Community members were open and stated that in the case of a death, they would proceed with their cultural rituals (e.g. watching over the body, taking the body to ancestral land). Religious leaders, spoke about referring cases to health workers, in case the person was suspected to be an Ebola case. For example, one Imam in Kisoro District spoke about protocols in case of an Ebola death:

"For us as usual we wash the body but where necessary, if someone dies of Ebola, we can give the body to the responsible people to be the ones to do the work. For us we cannot do anything because it is prevention. We cannot work on the body of Ebola because our religion does not allow us to commit suicide. You know the person has died of Ebola and then you touch it? Yes it is a tradition in Islam to wash the dead body but in cases where it is going to cause a negative consequence, we cannot do it."

Location of the interview: *Kisoro district, Bunagana at Uganda-DRC border*
Designation/ position: *Religious Leader Muslim*

Despite these assurances, it is not always clear when someone has died of Ebola, particularly if the person had not been to a health facility.

After the body is transported, family members and mourners spend time with the dead person. Visitors come and either sleep in the same room with the dead body or touch the body while mourning. In many districts (across cultures and religions), bodies are washed after death. During this cleansing ritual, there is a lot of contact with bodily fluids. In some places these rituals are handled by men. In others, it is the women who clean the bodies. For example, in Kagadi District, women are not allowed to get close to the grave:

"When a person in this community dies, the health worker does the last office, then after people have got their cultural beliefs and the family members perform the cultural rites and when they are done performing their cultural rites, there other rites that they perform and prepare the body and wait, when the time of burial reaches, the body is carried by the friends or family members to the grave. Women are not allowed close to the grave."

Location of the interview: *Kagadi district*
Designation/ position: *Community member - female*

Responses differed mainly based on religious beliefs, with specific traditions for Muslims, Christians, and those who follow a traditional belief system. Specific traditions are outlined below.

Table 8. Burial practices by cultural grouping and religion

Cultural Grouping	Religion	Burial Practice	Local Name
--	Muslim	1. Clear intestines/Wash body (Ghusl) 2. Perfume the sheets that cover body 3. Prayers/rituals (Salat-al-Janazah) 4. Shrouding/covering body (Kafan) 5. Burial of body (not in coffin)	1. Okunaza 2. Kalifuwa 3. Okusaalira 4. Okuziinga 5. Okuzika
--	Christian	1. Wash body 2. Put herbs/ preservatives on the body 3. Prayers/rituals 4. Burial of body	--
Alur	Local	1. Transport to clan Land 2. Men wash body 3. Prayers (including prayers for the dead) 4. Rituals 5. Burial of body	1. Kobere 2. Iyiel 3. Lega 4. Woro te kwaro 5. Yiik
Lugbara	Local	1. Transport to clan land 2. Men wash body 3. Prayers/rituals 4. Burial of body	1. Avu saa ori dria 2. Agupi eyi avu ma rua oji 3. Ezitaa 4. Ori owiza 5. Avu saza
Bafumbira	Local	1. Immediately after death: warm water, bathe body 2. Dressing of the body by relatives in cloth 3. Prayers/rituals 4. Burial of body	1. Umuntu amaze gumfa: Gushusha amazi, Gukarabya umumfu. 2. Abumury'ango bumumfu ku'mwambika imyambaro 3. Gusenga/Gukora imigenzo/amasubyo 4. Guhamba umumfu

Cultural Grouping	Religion	Burial Practice	Local Name
Batoro	Local	1. Touching the body 2. Bathe the body 3. Dress for burial 4. Prayers/rituals 5. Burial of body	1. Kwekwata omubiri 2. Okunabya Omubiri 3. Eeyura yokuzika 4. Okusaba na Obuhagwa 5. Kuzika Omutubi(Omufu)
Bakonzo	Local	1. Touching the body 2. Bathe the body 3. Dress for burial 4. Prayers/rituals 5. Burial of body	1. Erihambahamba Omubiri 2. Eryoya Omubiri 3. Eryambalya Omuholi 4. Erisabira ne'rithekatheka Omuholi 5. Eritsika Omuholi
Banyoro	Local	1. Spend night with the body 2. Clean the body 3. Dressing the dead body 4. Laying the dead body in the coffin 5. Paying last respects 6. Burial	1. Kwinganiza omutumbi 2. Okwogya omutumbi 3. Okujweka omutumbi 4. Kuteka omutumbi omusanduko 5. Okwiinamira omutumbi 6. Okuziika
Banyankore	Local	1. Preparing the body 2. Washing the body 3. Wrapping the body 4. Lifting the body 5. Actual burying 6. Mourning, crying while touching	1. Okutereza Omurambwe 2. Okwojya omulambwe/omufu 3. Okujweka omurambwe 4. Okukyiriza omurambwe 5. Okuzika 6. Okurira omufu/okukyura
Baganda	Local	1. Preparing the body 2. Washing the body 3. Washing the body's face with banana stems 4. Wrapping the body 5. Lifting the body 6. Actual burying 7. Mourning, crying while touching	1. Okugolola 2. Okunaza 3. Okuziraga 4. Okuzinga 5. Okusitula 6. Okuzika 7. Okungubaga

Regardless of culture or religion, burials in Uganda are a time of great risk for disease transmission. Specifically, burial practices also represent a potential for Ebola spread. This is true across all religions. Muslims wash and embalm the body and make it ready for burial, while Christians and traditional religions must do the same. In Nakivale Refugee Settlement, when a person dies, the body is taken to a health facility for a post-mortem and is prepared for burial there. It will take a great amount of effort to change the way these are done. In Luweero, we spoke to two Ebola survivors. They described the disrespectful way that their dead were "thrown into plastic bags" and buried in a place they did not know. Burials are a sacred time and great efforts must be taken to ensure that individuals' souls are at rest, as local communities believe.

4.6. Caretaking Practices and Gender

> *"Life and treatment start at home and then the hospital comes later"*
> (FGD with different local leaders in Luweero)

What does it mean to care?

Caretaking can mean different things and involve different actors and steps. In most cases caretaking starts at home, whereas decisions of seeking further care are made.

Participants from the study described caretaking at home to include providing the sick with food and water, washing their clothes and monitor their health. If the situation does not improve the Village Health Team (VHT) might visit the home. If there still isn't improved other care-seeking practices might be applied depending on the circumstances of the sick and resources of the family (see more under care-seeking practices). Caretaking can further include assisting financially to cover medical cost but not necessarily require financial resources.

Mothers as the primary caretaker, fathers as the primary decision maker

When a family member falls sick, the mother in the household is responsible for taking care of the sick person. The father of the household is often described as not being expected to physically participate in caretaking or out working. Nonetheless, despite the mom described as the primary caretaker, the father still plays a critical role in regard to caretaking. The father is described as the "implementer" in the household, and he therefore has the power to decide

when a sick family member should seek care outside the household. The father is further expected to cover all medical costs.

> *"Someone who cares at home is a woman, and then the man brings money to pay in the hospital."*
>
> (FGD with women at Rwenshama Landing Site)

Community Engagement

When a person in the household is sick it often involves and affect the entire community and not only the individual household. In case of severe illness, the community might contribute to the cost of treatment or provide means of transportation to the health facility and also visit with the affected family. An important actor of caretaking practices at home is the VHTs. The VHTs are described as trusted and respected health workers who know the community down to the specific households. They know if someone is sick and will often guide the families in what to do. The VHTs often work closely with local leaders, who will provide assistance if needed. Several communities describe how health workers, VHTs and local leaders work together to provide information about Ebola prevention at appropriate community meetings.

Other central actors in this community-collaboration are traditional healers and religious leaders. Religious institutions are being used as a platform to deliver health messages and religious leaders are being though about Ebola prevention. Despite traditional healers' different approaches towards treatment, the majority in this study were very open towards working together with health workers and local leaders to be able to detect signs and symptoms of Ebola to be able to refer potential cases to health facilities. In some areas, traditional healers on the other hand experienced conflicts with the formal health system, which hindered them in participating in training on Ebola.

> *"The work we do with them (health workers) is especially when we are teaching people, they come and we welcome them and give them a platform in the church to tell people the information they have."* (KII with Catholic leader in Bunagana)

Care-seeking practices

Multiple pathways of care-seeking

Care-seeking practices in Uganda are not static but change in response to the circumstances. The care-seeking behaviour of different households and communities are pragmatic and multiple. As described earlier the initial caretaking practices takes place at home. If the condition of the sick person does not improve other care-seeking practices will be initiated. Sources of care include public hospitals, private clinics, religious leaders and traditional healers.

A factor, that seems to influence peoples' care-seeking behaviour, is their access to health care. Barriers for accessing health care at a private or public health facility include lack of money, logistical barriers where people describe dying trying to reach the health facility, and expected low quality of care at the facility.

> *"...you go to (Name of health facility removed) a government health facility and you don't find there the doctors, you take there the whole day suffering and you end up coming back and the problem might worsen."* (FGD with women in Kagadi)

Alternative sources of care

As an alternative source of care either due to limited access to health care or because of specific beliefs people use alternative sources of care such as traditional healers and religious practices. Often traditional healers are described as the first source of care followed by health workers if the treatment by the traditional healer fails. Seeking care from a traditional healer does therefore not exclude seeking health care from a health worker as well. Trust in traditional healers is high, especially in rural areas where access to health facilities are limited.

> *"The patients see no reason for going to hospital for surgery yet they can get healed at church. In our cultures, some people believe that when they get sick, they have been bewitched, instead of going to health centers, they go to traditional shrines."* (FGD with different local leaders in Luweero)

Overall, these findings point to the need to engage women and men differently, in modalities that take into account their differing gender roles in the home. Further, the role of traditional

healers in communities must be acknowledged and efforts should be made to engage them in Ebola preparedness work.

4.7. Health Beliefs & Health-Seeking Behavior

This section covers the findings related to community and individuals' health beliefs and health-seeking behavior, with an underlying cultural and social component and with implications for Ebola preparedness. This was not an explicit part of the research, but it emerged organically as an important finding. Community members discussed the high cost of seeking health care in a facility. Others, especially those in rural areas, discussed the long distances to the nearest health facility and how local traditional healers were more easily accessible. These decision points are summarized in a decision tree in this section, which looks at health seeking decision-making practices.

Distance to health facility

A predominant response when community members were asked about barriers to seeking health care was that health facilities are often too far or too costly. This issue was not raised by health workers, but rather by community members themselves during FGDs (*n*=17). For example, in one FGD in Kagadi, a woman discussed that transportation fees were a major barrier to seeking care in a health facility:

Rural Uganda, where transportation is a challenge

> *"This is a hard area to reach, you find that a person is not able to climb the hill because of the hard complication is having, and advising that person to use water transport, the transport fee from Ntoroko to Fort Portal is also high and at times people die."*
>
> ***Location of the interview:*** *Kagadi District*
> ***Designation/ position:*** *Community Member - Female*

These responses differed by location and distance to the health facility - communities which had a health facility nearby were more easily able to access it. The responses differed by urban and rural areas, with urban areas having easier access to health facilities and rural areas having difficulty in accessing the health facility.

"We can easily die because we don't have a nearby health facility where we can run to but our leaders like chairmen care about us, they will involve the higher authorities and they will help us."

"We are on the lake shores, there is no way of getting treatment, what can we do? Maybe calling the higher authorities for help but if there is no way, then people will die."

Location of the interview: *Kagadi District*
Designation/ position: *Community Members - Two Females*

Even what may seem like a small transportation fee of 5,000 Uganda shillings was actually quite a lot of money, especially in rural areas. One man discussed the issues with transportation and other fees in Hoima:

"When you don't have money at home, it is a very big problem because there is no way you can take the sick person to the health facility and also the patients differ, you might find that you have a pregnant wife and finding a means of transport to the facility when you don't have money, you can only run and borrow from a friend, look for a vehicle and you can't afford and then opt for a boda boda, transporting a pregnant woman on a motorcycle is dangerous and risky. The VHT'S first of all don't know how to inject someone because they are not taught how to administer injections and at times they have no medicines too."

Location of the interview: *Hoima District*
Designation/ position: *Community Member - Male*

Attitude & perceived arrogance of government health workers

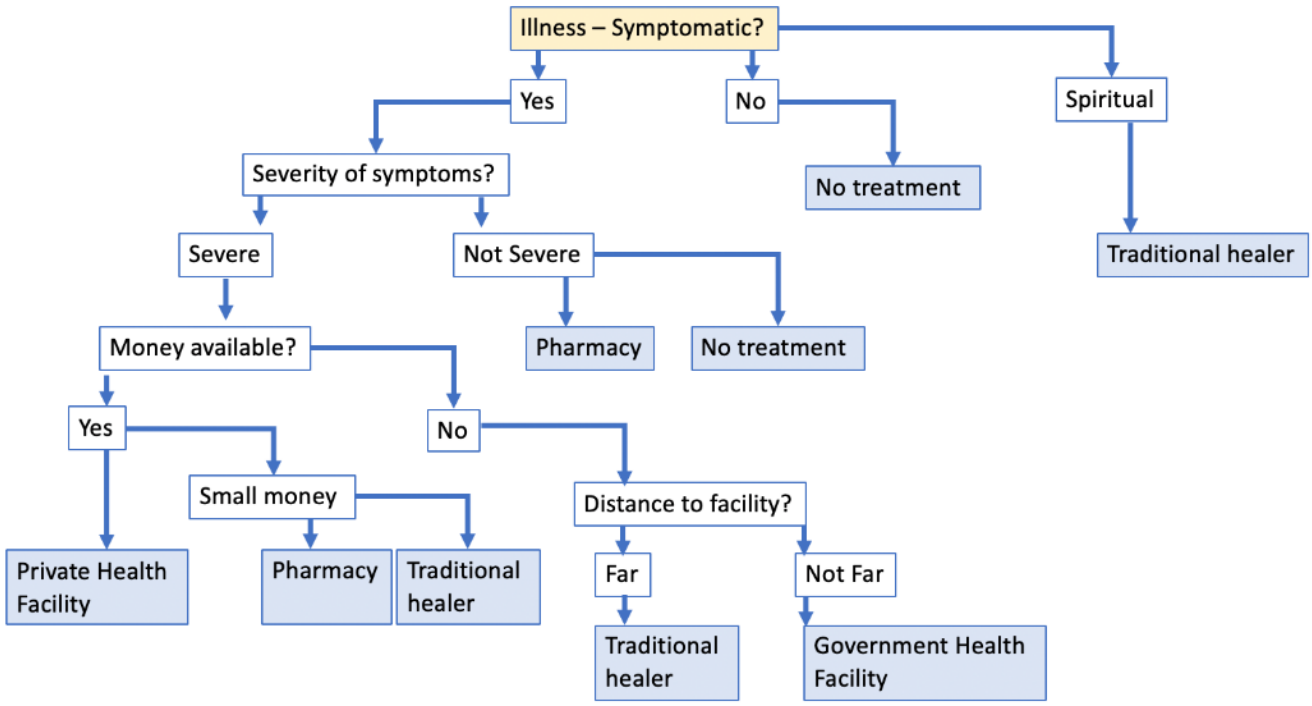
Other community members discussed the behavior of health workers at government health facilities, as a major barrier to seeking care. Government health workers were often cited as rude, inattentive, uncaring, unconcerned, and so on. Community members travel long distances or use a lot of transport to reach health facilities, and yet, upon reaching, health workers are often inattentive. Whether this is due to an overflow of patients or other reasons, health workers are perceived as rude. This makes it much less likely that community

members will seek care from a government health facility, even during emergency times. One person described the behavior of health workers:

> *"I have ever gone to the health facility, there are very many nurses that are gracious, but they also others who are not gracious, You will there like maybe you are pregnant and you have gone for delivery, you go to Ntoroko and after reaching there, you have your own suffering and **the nurse also is very rude on you**, do such and such, am I the one who impregnated you, and **that's why many of us fear going to the health facilities** especially the government one. Even during the time of maternity, they say a lot of things like this one is un hygienic, you reach at the facility, but instead of first working on those that come from very far, they first work on those that are in the same area with the health facility and this may lead to a pregnant woman spending 6 to 7 months without going for maternity."*
>
> ***Location of the interview:** Kagadi District*
> ***Designation/ position:** Community Member - Female*

Here, we can note how community members' future health decision-making is affected by a previous poor experience at a health facility. The community member differentiates between government and private health facilities - with government health facilities having an even worse reputation for its health workers' behavior toward patients. Below, the figure details the decisions that individuals make when choosing to seek care, where, and how. These decision points emerge from the community member FGDs and the rationale they describe for seeking care, or not, based on a number of factors (cost, distance, illness severity, etc.).

Figure 9. Health care decision points in high-risk districts in Uganda



4.8. Trust between the Community and Officials

This section details the findings related to community trust in officials - local leaders, health workers, security personnel, army - and its relation to Ebola preparedness. All FGDs (*n*=25) and key informant interviews with local leaders (*n*=14) and health workers (*n*=44) covered these topics. We noted important regional differences. Trust in local leaders was generally high, and local leaders were seen as a source of trusted information on Ebola prevention. Trust in health workers was medium, with many community members complaining that government health workers in particular were not to be trusted. Red Cross and UNICEF staff were seen as an important source of support to communities, most likely because of the programs that they bring to communities. In fishing communities, there was generally a lot of mistrust in authorities, particularly the army. These nuances are discussed further below.

Trust in Local Council I members

Local leaders, particularly Local Council I members, are seen as trusted and integral components of a community's fabric. Where local leaders had been engaged, they were an important group to disseminate information on Ebola prevention and control - spreading messages about hand washing, screening, and how to report a suspected case. In areas such as Arua & Pakwach, where not much Ebola preparedness work has been done, local leaders were described as not really doing much.

> *"The local leaders here are not yet concerned about Ebola maybe because it has not yet been detected here. None of the local leaders have been seen on the ground addressing people about Ebola. There is no any work local leaders are doing to prevent Ebola at the moment."*
>
> ***Location of the interview:*** *Pakwach District*
> ***Designation/ position:*** *Community Members - Youth*

In areas where Ebola preparedness is ongoing, community members complained about other officials not working with local leaders. Resident men of Hoima District described the procedures that should be followed to ensure chains of command are respected, while also demonstrating respect for their local leaders.

> *"The emigration officers don't respect the leaders,* ***the most important person in the community is the Chairman LC 1****, the support that am talking about that should be given to them is that when people are coming from Congo and the emigration officer does his/her job without a representative of the Local Council because the emigration officers maintain that they are appointed but even when they are appointed before they commence their work, they first report to the chairman but time comes when they start do their work without informing the president of the area, so the chairman and the council should get support such that all the people that do work in this areas like emigration officers,* ***the chairman must be aware of the work that they are doing.****"*
>
> ***Location of the interview:*** *Hoima District*
> ***Designation/ position:*** *Community Members - Men*

At Rwenshama Landing Site, women similarly displayed a sense of trust in local leaders, especially related to teachings on Ebola. They relate the lack of Ebola in their area to the good work that the local leaders are doing.

> *"In teaching …about Ebola, they [local leaders] have brought for us taps, drugs to put in water so that when you enter our country you first wash hands to prevent Ebola. They have tried to bring even drugs at the government health centers. They have fought for us because in our area no one has ever been infected with Ebola****.****"*
>
> ***Location of the interview:*** *Rwenshama Landing Site, Rukungiri District*
> ***Designation/ position:*** *Community Members - Women*

Overall, community members' responses demonstrate the importance of working closely with local leaders, both to ensure that Ebola messaging is well-received at the community level and to promote sustainability of prevention efforts. Meanwhile, the local leaders themselves (*n*=14) are quick to describe their openness to Ebola prevention messaging. They only ask for additional support, messages, posters, and where needed, materials, to do this work. Local leaders see it as a part of their job, to ensure that Ebola does not reach the communities where they work. They are very aware of the risks of Ebola and are eager to participate in preparedness activities.

Trust in government biomedical health workers

Community members' perceptions of health workers were highlighted in the previous section. Here, we continue with this theme, discussing how government health workers are perceived,

with implications for trust. Government health workers would not be the most trusted individuals to disseminate knowledge or as a source of Ebola prevention and control information. In one focus group in Pakwach District, 60% of individuals described not having a good opinion of health workers. When asked to elaborate on the subject, they described how health workers act "arrogant" at work:

> *"The problem they encountered with health workers basically stems from how they segregate people especially in government facilities and **they are arrogant** at work. Additionally, 1 person out of 10 talked about how they steal drugs supplied by government."*
>
> ***Location of the interview:*** *Pakwach District*
> ***Designation/ position:*** *Community Members - Youth*

While health workers may be an important stakeholder in Ebola preparedness and response, it is important to understand community's perceptions of government health workers and how this might influence any kind of trust they have in the information that is disseminated by those groups.

Trust in NGO workers

In the KIIs, 28 individuals mentioned the good work that NGO workers and UNICEF is doing to prevent Ebola in their areas. Often seen as impartial mediators in the Ebola response, NGO workers are well-received by community members. Specifically, the work of the WHO, the Red Cross, and UNICEF, along with IDI were mentioned during interviews. However, when community members discussed the work of NGOs, they often mentioned that NGOs do not always "reach the ground". Community members asked for additional sensitization activities, additional information, and even Ebola vaccines.

Trust in authorities among fishing community members

As discussed earlier, responses on trust in authority differed regionally. Special attention must be paid to the dynamics in fishing communities, where trust in authority figures is very low - particularly army soldiers. Due to the historical and political context in fishing communities (discussed in Section 4.9), fishing communities are wary of authorities. Fishing communities are being asked to pay exorbitant fees to buy bigger boats, register existing

boats, and so on. Individuals are getting deep into debt just to be able to conduct their daily work of fishing. In these areas, trust in authorities is very low and many participants even expressed wishes that Ebola should come there and kill them, so that they do not have to pay back a loan they cannot afford.

What emerges from these findings is a map of community trust in local and national stakeholders, with implications for Ebola preparedness planning.

"Now we people at this landing site we are suffering, they came and told us that they don't want small boats, they destroyed small ones, we were told to get big boats and 5-inch fishnets. So, we went to the bank for loans, we bought boats, Engines and nets as they wanted so after passing the test they had given to us, we started fishing, then there came these people of numbers, the Bahima and they said we cannot fish they want their numbers, they sailed boats and put them in the bush, ***loans are squeezing us and to get that boat on water, you need like 20 million but it's a loan remember****, you are forced to park your boat, they have taken your number, so if you are the one what would you think of?"*

*"Yah even that one is also there. Because when I go to Congo****, I don't even think that Ebola is there because even if Ebola killed me, it would have saved me from that loan****. I can be having a loan, it is on my neck so even if Ebola killed me, it would have saved me from that loan. We are in bad situation, we spend the whole day crying we don't have what to do, we don't have what to eat.* ***The situation here is just to kill me, like even the dead is better than us.****"*

Location of the interview: *Rwenshama Landing Site, Rukungiri District*
Designation/ position: *Community Members - Women*

Table 9. Community trust in local and national stakeholders

Low Trust	Medium Trust	High Trust
Government health workers	Traditional healers	Local leaders
Army	Village Health Teams	NGO workers
Security officers	--	Private health workers
Customs officers	--	Religious leaders

Low trust as derived from the data is defined as communities having low trust in a stakeholder's reliability in a variety of situations. Medium trust is defined as communities having a medium level of trust in a stakeholder's reliability. Similarly, high trust is when communities demonstrate a high willingness to cooperate with stakeholders and discuss the reliability of stakeholders.

Conclusions

The local, district, and national efforts to engage in EVD sensitization and preparedness are overall well-received by community members. However, a lack of resources – particularly financial and staff, hamper the EVD sensitization efforts. For example, one local hospital administrator talked about the challenges that EVD preparedness places on his budget. He had to allocate funds from other ongoing work in the budget in order to make room for EVD preparedness. Yet, ongoing challenges such as Crimean-Congo Hemorrhagic Fever (CCHF) and Rift Valley Fever (RVF) - of which there have been several cases in these high-risk districts - are not well attended to. The hospital administrator talked about the limits on the budget, and how EVD preparedness had placed undue strain on finances. They even have had to borrow from the next fiscal year in order to prepare for Ebola. While conducting observations (see Female Research Assistant in Picture below), it was noted that the hospital was not well prepared for Ebola - with patchwork prevention at the gate and an inadequately supplied isolation building. In other places, religious leaders were not well engaged in Ebola preparedness. These trusted leaders of the community should be better engaged in order to deliver messaging around safe burials and other behavior change. The importance of engaging trusted local leaders such as religious leaders has been illustrated elsewhere in the same region (Sewankambo and Mafigiri, 2017; Downs et al, 2017) and should therefore be considered during the EVD preparedness process. Finally, there were challenges noted in the private sector. Private health facilities and pharmacies in the high-risk districts have not been reached with EVD preparedness - staff at these facilities noted that they were promised a potential EVD vaccine but they overall felt very unprepared for Ebola.

An Ebola screening tent at Salam Sala, Northwest Uganda

4.9. Social, Political, and Economic Context

This section details other aspects of the findings, related to the broader social, political, and economic context in the study areas.

Health systems

Throughout our fieldwork, we noted that underfunded and understaffed health systems will impact preparedness for EVD in high-risk districts. Often, government health facilities were underfunded and located in areas that were inconvenient for local residents to access. In Bunagana, someone with a case of EVD would need to climb a hill and walk very far just to reach the Health Facility II. It would be easier to attend a private clinic in town.

Fishing communities and conflict

A fishing boat, Southwest Uganda

Furthermore, the issue of water along border areas impacts the cohesion of populations and trust in government. In Rukungiri-Rwenshama, there is conflict about shared waters with implication for EVD prevention. In the same areas, women noted that they took out loans to buy boats but cannot pay those loans back because the government captured their boats. This is confirmed in other fishing areas, where it is standard practice for government soldiers to break boats that are fishing illegally on the waters. Some of the women went so far as to note that "they wished they could die of Ebola" rather than survive and struggle to pay back their loans.

"Barriers are so many. One is money; if one has no money then it is difficult for him or her to go to the health center. Then two, it is some people think or feel when you get any form of sickness, you don't feel that it is serious not until one maybe can totally fail to get up. But one thinks anytime it will heal on its own even without going to the health center and some people even buy drugs on their own thinking maybe I am feeling some malaria then he or she buys some drugs and takes before even seeking advice from a doctor."

Key informants' interview with Traditional Healer, Bunagana Border.

Further, in Rukungiri and Kanungu Districts, many suspected cases of Ebola died shortly after reaching the hospital - this raised the level of alarm and fostered mistrust of health care system.

Refugee flows from DRC to Uganda

Moreover, in areas that are host communities to refugees, the host community noted that refugees receive much more support, creating an unfair power balance and exacerbating ethnic tensions. For example, near Nakivale Refugee Settlement, there was recently drought. While the Ugandans starved, the Congolese refugees received emergency food supplies and medical treatment. This situation has stuck in the minds of the host community, as they see more support going to "foreign" individuals rather than to themselves. It is important to note that these conflicts could hinder Ebola preparedness, as social cohesion is important to improving the uptake of Ebola prevention messages.

After visiting the Office of the Prime Minister (OPM)'s Refugee Desk Officer in Arua District, we were linked up with the head of the Kuluba Collection Center in Koboko District. We visited the collection center, and different border crossings, at the border of South Sudan, DRC, and Uganda. Individuals noted that in this chaotic area, many South Sudanese cross first into DRC, and then into Uganda, seeking refuge from war. Once they cross over at Salam Sala or another border crossing and declare they are seeking refugee status, they are taken to the Kuluba Collection Center for care, services, and screening. The staff at Kuluba spoke about issues of Ebola preparedness, but they had other pressing concerns, such as psychosocial support, physical and psychological post-trauma care.

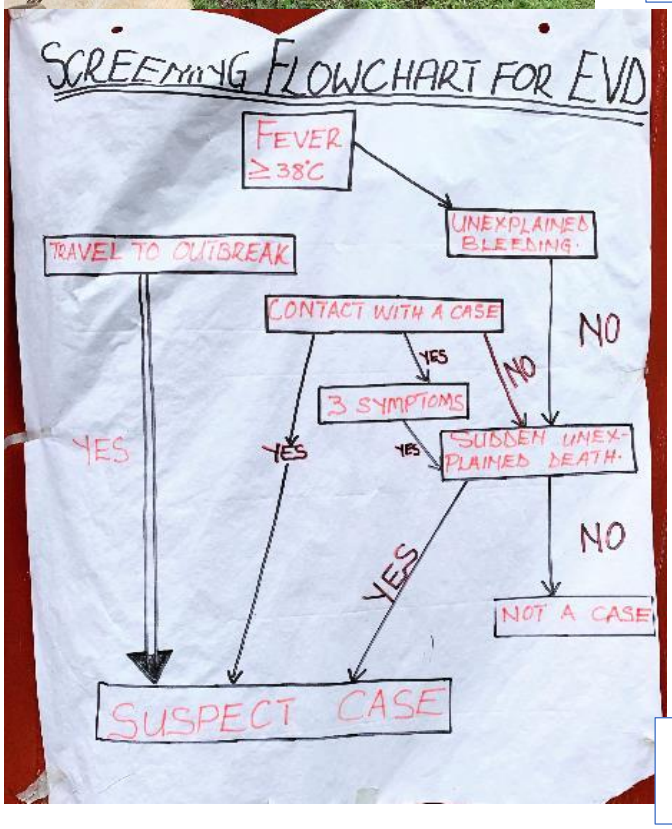
Border dynamics and Ebola preparedness

The primary and often only preparedness measure in place along the border, are screening points at formal points of entry. At these formal entry points, individuals crossing from DRC into Uganda, and vice versa, must pass through a screening point. Typically, this includes stepping in a bucket with bleach, washing hands with chlorine, and getting your temperature checked. In most places, only the temperature and hand washing are in place. While this would identify those crossing formal border points, informal border points (which are used far more frequently) have absolutely no kind of preparedness. Overall, the research team agreed that preparedness measures are not enough. Many additional health workers need to be vaccinated (ex. in Vurra), others need to be properly facilitated to boost morale (ex. in Salam Sala), and all screening points need well-equipped isolation tents. There should also be more clear protocols for transporting a suspected Ebola case.

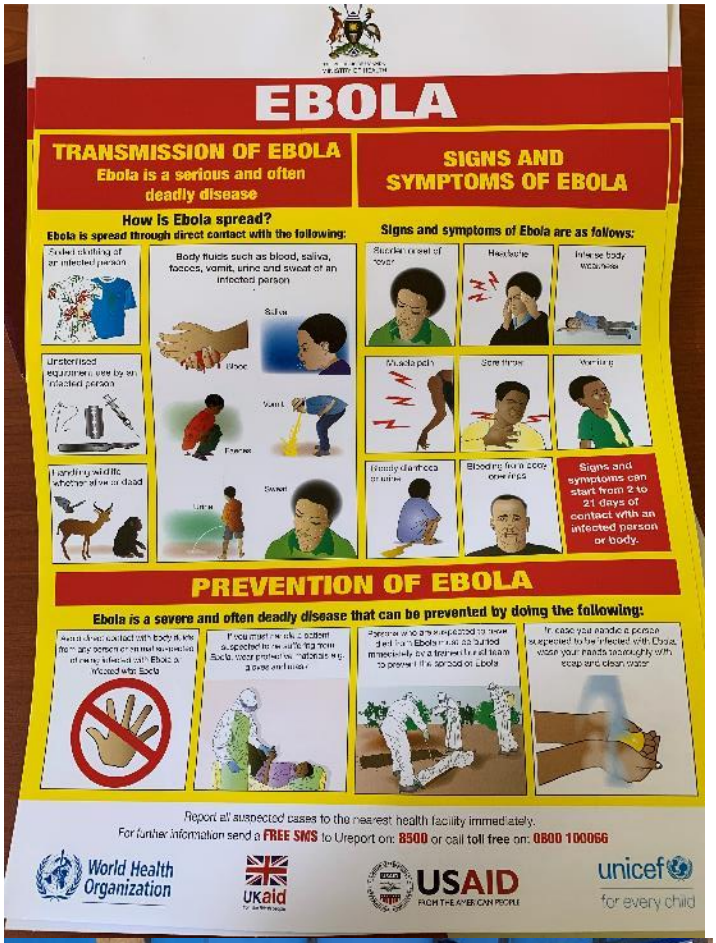
> *"There are screening and hand wash facilities at the border, even us we are sensitizing people on hand wash, avoid eating dead animals, etc. it's true we are supposed to help in this awareness as traditional healers."*
>
> ***Key informants' interview with Traditional Healer, Bunagana Border***

Many people whom we spoke to were concerned about the outbreak and along the border - they are very aware of the outbreak of Ebola in DRC. However, people also describe the pressing concerns of day-to-day life, which almost always supersede taking precautions against Ebola. In Bunagana, there is no regular access to water on the Ugandan side, and so individuals must cross in DRC to get water. At all border points, the divisions between DRC and Uganda are artificial. In these border areas, people intermarry, intermingle, trade, and co-exist across borders. In other words, there is a lot of movement of people. That will not stop because of Ebola. Moreover, many people trade, drive trucks, or *bodas* across international borders. These individuals will not stop their work because it provides them with a livelihood that they need to survive.

A hand washing station, Kisoro Hospital



A screening flowchart for EVD, Kasese District



Ebola posters in the field

Part Five: Discussion

5.1. Introduction

This report has detailed how livelihood practices, religious and traditional beliefs, burial practices and funeral rituals impact Ebola preparedness and potential spread in high-risk districts in Uganda. Moreover, this report has looked at how stakeholder efforts are received at the community level and we have identified areas for improved rapport and trust. Finally, we have looked at aspects of the social, political, and economic context which could impact Ebola preparedness in Uganda.

This section puts the findings in context, examining how the findings are underpinned by theoretical constructs of the ecological model, the health-belief model, and structural violence. First, we discuss evidence of constrained agency. Then, we look at health beliefs and stakeholder trust. Finally, we look at how marginalization structures individuals' capacity to respond or take action for Ebola preparedness.

5.2. A Cultural Context of Ebola in High-Risk Districts: An Ecological View

In this report, we have examined how cultural norms of livelihoods, religious beliefs, burial practice, caretaking practices, and health beliefs influence the potential for uptake of Ebola preparedness messaging. Across the board, in high-risk districts, we can consider the multilevel influences that policies, communities, social networks, and individuals (CDC, 2014) have on Ebola preparedness. Although individuals expressed concern about crossing into Ebola endemic regions of the DRC, many have to routinely cross to visit family, tend crops, fetch water, and trade at the market. Individuals' health beliefs are also affected by these multilevel influences, in turn, influencing how individuals perceive that they are at risk for Ebola (Glanz, 2010). We heard from community members that they are worried about Ebola, from Arua District in Northwest Uganda along the border to Kisoro District in Southwest Uganda. Communities are worried and perceive themselves at high-risk of Ebola, especially in areas in constant contact with migratory or Congolese populations. However, communities complain that they do not have access to health facilities, they were not vaccinated, and they cannot stop crossing into the DRC. Furthermore, local leaders and other highly trusted stakeholders must be routinely engaged in Ebola preparedness in order to

ensure that messages are taken up by the community. Having identified these trusted stakeholders, it would be important for staff working on Ebola preparedness to routinely engage with them.

5.3. Social, Political, and Economic Context of Ebola in High-Risk Districts: Structural Violence

Moreover, what emerged from this research is the ways in which the social, political, and economic context configure decision-making with implications for Ebola preparedness. We heard from rural communities that have no access to health facilities, and during times of illness rely on traditional healers. We also heard from fishing communities, where longstanding conflict with the government and authorities has the strong potential to impact how they view and act on Ebola. Special attention must be paid to fishing communities, where the dominating view is that Ebola is just another injustice that is actually not as bad as the structural violence (Galtung, 1990) that is inflicted upon them, through exorbitant loans and restrictions on fishing. Similar to the context of Ebola in conflict areas of the DRC, fishing communities have a high-risk of Ebola spread due to their marginalization and the likelihood that they would not have the capacity to act to prevent or contain Ebola. While conducting this research with communities, we noticed that the rural poor and those living in landing sites were experiencing the most structural violence, with little power and high vulnerability (Farmer, 2004). Ebola is, similar to HIV, an "epidemic of opportunity," that is visible in communities most affected by structural violence - from West Africa to the DRC.

Part Six: Conclusions and Recommendations

6.1. Introduction

In summary, our study raises serious concerns about the observed areas' preparedness for an Ebola outbreak, with differences within the high-risk districts. This study identified particularly vulnerable communities due to experiences of structural violence - from rural poor to fishing communities. Issues such as lack of water and sanitation, other ongoing health threats (RVF, CCHF, etc.), lack of food stability, and poverty contribute to community vulnerability. Conflict or discord between refugees and host communities could present a challenge to EVD preparedness and uptake of EVD messages. The study noted specific recommendations or challenges that can inform UNICEF's C4D work, including work on Risk Communication and Social Mobilization.

6.2. Policy and Program Recommendations

This work specifically responds to the UNICEF C4D's recommendations on EVD preparedness for Uganda's high-risk districts (2018), including to:

(1) *Scale up risk communication to engage village health teams and Uganda Red Cross society volunteers to improve social mobilization at the community level.* This research will result in actionable steps to improve the cultural efficacy and uptake of risk communication messages. Further, this research will disseminate actionable and evidence-based steps to incorporate the social and cultural context of risk communication and social mobilization efforts. By examining leverage points within the community, this research will help to tailor EVD preparedness efforts.

(2) *Train additional teams staffed with local community members for safe burials in high-risk districts.* By assessing existing burial practices and identifying leverage points for behavior change, this research will enable practitioners to encourage safe burial practices during times of high-risk of EVD transmission and whenever appropriate.

Further, this work links into the EVD Monitoring Framework (MoH 2018), specifically Result Areas 2 (enhanced community awareness) and 3 (case management, infection prevention, and safe burials.

On Risk Communication and Social Mobilization

- Our study noted that the preferred mode of communication is through the radio and mobile phones (e.g. through SMS).
- Specific "risk behaviors" for the spread of Ebola include: consumption of game meat, a lack of frequent handwashing, traditional burial practices, health seeking behavior, migration and travel, and the use of traditional healers for treatment.
- Translate messages into local languages and should offer solutions not just "practices to avoid". Our study calls this a "harm reduction" approach to Ebola preparedness. In other words, due to significant barriers (e.g. livelihoods) to taking up Ebola prevention measures, it is important that we demonstrate ways to *safely* conduct burials or hunt for bushmeat. If we persist with a "stop" all behaviors approach, the uptake will be low and individuals will not comply with recommendations.
- Participatory social mobilization practices (e.g. involving local leaders) would ensure sustainability and uptake of EVD messages.
- Address stigma against Congolese, and emphasize that Ebola can be spread by anyone.
- Pay special attention to the local dynamics of landing sites, where fishing communities are in conflict with authorities.
- Design messages to address the practice of self-medication from pharmacies/drug shops and improve reporting to health facilities. Additionally, engage drug stores, pharmacies, private health facilities in EVD prevention & preparedness.
- Design posters for illiterate individuals, with well-designed photos to communicate messages.
- Design posters in additional local languages, and children-friendly messaging.
- Address the concerns of pregnant women including their issue with the Chlorine smell at hand-washing stations and perceptions about the potential danger of the Ebola vaccine for among pregnant health workers.

- Engage the youth in EVD prevention and preparedness activities including when designing youth-friendly mobilization practices, with the participation of local youth. Use songs, dances, and so on, to communicate messaging about Ebola.
- Engage Ebola survivors in spreading messaging in their communities.
- Design risk communication that focuses on other symptoms and emphasizes that not all individuals with Ebola have hemorrhaging.

On Trusted Sources of Information

- Village Health Workers were also cited as a trusted source of information.
- Key influencers in border districts include: local leaders, NGO workers, private health workers, and religious leaders.
- Map community stakeholders in each community and engage those who are trusted.

On Caretaking Practices at Home and in the Community

- Sensitization of the community must be sensitive to local conditions, relationships and power dynamics. This include using existing structure in the given area to deliver health messages. In some areas, this might mean to deliver health messages through the church whereas other structures might be more appropriate to use in other areas.
- Most health care and treatment take place at household level and is done by women. Health workers need to reach out and work close together with women in general and specifically in regard to Ebola prevention.
- Provide a hotline (cell phone/radio free of charge) to help women make decisions about care at home.

Care-Seeking Practices

- More needs to be done to engage traditional healers, particularly in rural areas where these individuals are the first point of care. The traditional leaders should be trained to function as positive agents for behavior change towards Ebola preparedness.
- Mapping of the different types of traditional healers to enhance collaboration with local leaders. This will both be beneficial in the preventive stage of Ebola as well as enhance an effective surveillance tool in case of an Ebola outbreak in Uganda.
- Training and engagement of more VHTs. Due to limited access to health care facilities VHTs are critical to enhance Ebola preparedness in hard to reach areas.

Adoption of Protective Behaviors

- Information towards adoption of protective behaviors should be authentic and pragmatic.
- Enhance sensitizing and training targeting individuals working in the transportation sector (i.e. *boda boda* and *taxi* drivers) to bring attention to the risk of transporting dead bodies.
- To avoid creating fear of greeting friends and family members, the community including religious and local leaders should be engaged to develop alternative safe and cultural appropriate greetings.

6.3. Dissemination of research

Results will be distilled into digestible and short briefs that can be read by stakeholders. These briefs can be created for *each* cultural grouping and/or organized topically. These briefs (again, for each cultural grouping) will focus on different topics, such as burial practices or economic context. Each brief will end with recommendations for risk communication and social mobilization activities so that practitioners have actionable points to work with. Results will be disseminated during one-on-one briefings with appropriate Task Force bodies and implementing partners to facilitate uptake of social and cultural information into risk communication and social mobilization programming. Results will also be disseminated in relevant social science circles, online and in person, to streamline research efforts on EVD on the Uganda-DRC border. Efforts should be made to connect with DRC social science researchers to integrate findings and share knowledge across borders. Risk communication and community engagement is essential for any disease outbreak response. This is particularly critical during Ebola outbreaks, which create a large amount of panic and fear in the public. Moreover, this fear impacts the ways in which risk communication and other health work is received by the community.

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Appendices

1. Ethical Approvals

MAKERERE UNIVERSITY

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COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
SCHOOL OF SOCIAL SCIENCES
RESEARCH ETHICS COMMITTEE

Your Ref:
Our Ref: MAKSS REC 01.19.252

11th February 2019

David K. Mafigiri, PhD., MPH
Principal Investigator (MAKSS REC 01.19.252)
Makerere University School of Social Sciences
Telephone contact: (+256) 793 371781)
Email: dmk28@case..edu/mafigiridk@yahoo.co.uk

Dear Sir,

Initial – Full Board
Re: Approval of Protocol titled: "*Strengthening Community Linkages to Ebola virus Disease (EVD) outbreak preparedness in Uganda*"

This is to inform you that, the Makerere University School of Social Sciences Research Ethics Committee (MAKSS REC) granted approval to the above referenced study. The MAKSS REC reviewed the proposal using the full board review on **1st February 2019**. This has been done in line with the investigator's subsequent letter addressing comments and suggestions.

Your study protocol number with MAKSS REC is **MAKSS REC 01.19.252.** Please be sure to reference this number in any correspondence with MAKSS REC. Note that, the initial approval date for your proposal by **MAKSS REC was 1st February 2019**. This is an annual approval and therefore; approval expires on **31st January 2020. Please note that, final approval should be done by Uganda National Council for Science and Technology. You should use stamped consent forms and study tools/instruments while executing your field activities at all times.** However, continued approval is conditional upon your compliance with the following requirements.

Continued Review
In order to continue on this study (including data analysis) beyond the expiration date, Makerere University School of Social Sciences (MAKSS REC) must re-approve the protocol after conducting a substantive meaningful, continuing review. This means that you must submit a continuing report
Form as a request for continuing review. To avoid a lapse, you should submit the request six (6) to eight (8) weeks before the lapse date. Please use the forms supplied by our office.

Please also note the following:

- No other consent form(s), questionnaires and or advertisement documents should be used. The Consent form(s) must be signed by each subject prior to initiation of my protocol procedures. In addition, each research participant should be given a copy of the signed consent form.

Amendments

During the approval period, if you propose any changes to the protocol such as its funding source, recruiting materials or consent documents, you must seek Makerere University School of Social Sciences Research and Ethics Committee (MAKSS REC) for approval before implementing it.

Please summarise the proposed change and the rationale for it in a letter to the Makerere University School of Social Sciences Research and Ethics Committee. In addition, submit three (3) copies of an updated version of your original protocol application- one showing all proposed changes in bold or "track changes" and the other without bold or track changes.

Reporting

Among other events which must be reported in writing to the Makerere University School of Social Sciences Research and Ethics Committee include:

i. Suspension or termination of the protocol by you or the grantor.
ii. Unexpected problems involving risk to participants or others.
iii. Adverse events, including unanticipated or anticipated but severe physical harm to participants.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and commitment to the protection of human subjects in research.

The legal requirement in Uganda is that, all research activities must be registered with the National Council for Science and Technology. The forms for this registration can be obtained from their website www.unsct.go.ug

Please contact the Administrator of Makerere University School of Social Sciences Research and Ethics Committee at makssrec@gmail.com OR bijulied@yahoo.co.uk or telephone number +256 712 207926 if you counter any problem.

Yours sincerely,

Dr. Stella Neema
Chairperson
Makerere University School of Social Sciences Research and Ethics Committee

Makerere University School of Social Sciences * Research Ethics Committee *
Valid Thru
31 JAN 2020
APPROVED

c.c.: The Executive Secretary, Uganda National Council for Science and Technology

THE REPUBLIC OF UGANDA

OFFICE OF THE PRESIDENT

PARLIAMENT BUILDING P.O. BOX 7168 KAMPALA,TELEPHONES: 254881/6, / 343934, 343926,343943, 233717, 344026, 230048, FAX: 235459/256143
Email: secretary@op.go.ug, Website: www.officeofthepresident.go.ug

ADM 194/212/01

April 4, 2019

The Resident District Commissioner, Ntoroko District
The Resident District Commissioner, Kasese District
The Resident District Commissioner, Kabarole District
The Resident District Commissioner, Bundibugyo District
The Resident District Commissioner, Bunyangabu District
The Resident District Commissioner, Kanungu District
The Resident District Commissioner, Kisoro District
The Resident District Commissioner, Rukungiri District
The Resident District Commissioner, Isingiro District
The Resident District Commissioner, Buliisa District
The Resident District Commissioner, Hoima District
The Resident District Commissioner, Kagadi District
The Resident District Commissioner, Pakwach District
The Resident District Commissioner, Arua District
The Resident District Commissioner, Kampala District
The Resident District Commissioner, Wakiso District

RESEARCH CLEARANCE

This is to introduce to you **David Karim Kaawa-Mafigiri** a Researcher who will be carrying out a research entitled **"STRENGTHENING COMMUNITY LINIAGES TO EBOLA VIRUS DISEASE (EVD) OUTBREAK PREPAREDNESS IN UGANDA"** for a period of **12months** in your district.

He has undergone the necessary clearance to carry out the said project.
Please render him the necessary assistance.

By copy of this letter **David Karim Kaawa-Mafigiri** is requested to report to the Resident District Commissioners of the above districts before proceeding with the Research.

Musagazi Deogratius
FOR: SECRETARY, OFFICE OF THE PRESIDENT
Copy: David Karim Kaawa-Mafigiri

Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

UNCST

Our Ref: SS 4910 **15th March 2019**

Dr. David Kaawa – Mafigiri
Principal Investigator
Makerere University
Kampala

Dear Dr. Kaawa – Mafigiri,

Re: Research Approval: Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda

I am pleased to inform you that on **05/03/2019**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **05/03/2019** to **05/03/2020.**

Your research registration number with the UNCST is **SS 4910.** Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local IRC for review with copies to the National Drug Authority.
4. Unanticipated problems involving risks to research subjects/participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST review.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

LOCATION/CORRESPONDENCE

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WEBSITE: http://www.uncst.go.ug

Uganda National Council for Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Below is a list of documents approved with this application:

	Document Title	Language	Version	Version Date
1.	Research proposal	English	2.0	February 2019
2.	Parental/Guardian Informed Consent Form (ICF) on behalf of children aged 10 – 17 years	English	1.0	February 2019
3.	Assent form for children aged 10 – 17 years	English	2.0	February 2019
4.	ICF for Key Informant Interviews (KIIs) with stakeholders	English and Rufumbira	1.0	January 2019
5.	ICF for KIIs with stakeholders	Lukhonzo	2.0	February 2019
6.	Observation checklist	English	2.0	February 2019
7.	Focus group discussion guide for community members	English	2.0	February 2019
8.	KII guide for stakeholders	English, Lukhonzo and Rufumbira	1.0	January 2019

Yours sincerely,

Isaac Makhuwa
For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Copied to: Chair, Makerere University School of Social Sciences, Research Ethics Committee

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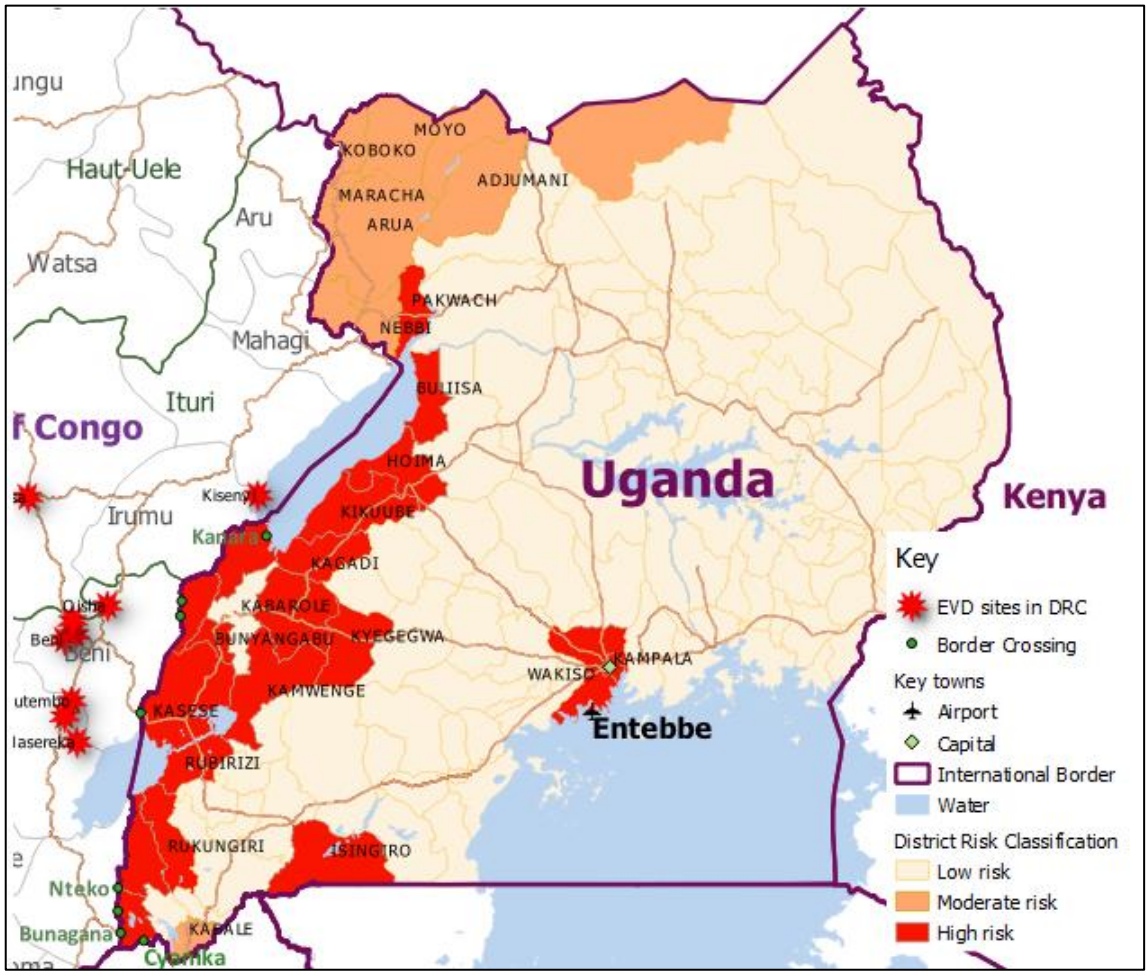
2. Map of High-Risk Districts in Uganda



From "EVD Preparedness Update," Ministry of Health Uganda, 14th March 2019.

3. Focus Group Discussion Guide

FOCUS GROUP DISCUSSION GUIDE FOR COMMUNITY MEMBERS

Study title: "Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda"

Study Investigators: David Kaawa Mafigiri, PhD, MPH
Center for Social Sciences Research on AIDS (CeSSRA)
School of Social Sciences, Makerere University
P.O. Box 663 Kampala, dmk28@case.edu
Telephone number 0793371781

Version 2; 6th February 2019

FGD GUIDE FOR COMMUNITY MEMBERS

"Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda"

Interview Date: ..... **Start time: .....**

Participant ID No.: .....

Topic Focus	Core Questions	Additional Questions or Prompts	Suggested Expansion Material
Work history	• What work do you do and for how long? • Are there other types of work that you are doing? Are there other places you get money? • How many hours do you work per week? • Do you work every day or once in a while? How often?	Prompt: describe an average day of work	Livelihood barriers and facilitators to health-seeking behavior and Ebola preparedness
Religious beliefs	• What are some of the religions or religious beliefs in this community? Please describe each. • Does your religion have any explanation for Ebola?	Prompt: describe an example of your religious beliefs and how they influence your decisions	Community religious norms and leaders
Burial practices and social norms	• When someone here dies, how are they buried? How is the body prepared for burial? How is the body washed and cleaned? Who does that work? • What do people here believe about death and burials? What do you believe?	Prompt: describe a recent death and describe what happened after the person was found dead Prompt: who exactly is involved at each step of the burial	Openness to shifting burial practice based on Ebola risk
Caretaking practices	• Who is mostly responsible for taking care of other men, children? What about sick people and children?	Prompt: describe a recent case of a sick person, what happened, and who took care of that person	Linkage to health facilities Barriers to visiting a health

	• Who else is involved in taking care of a sick person? Who makes decisions on when/if to go to the hospital? • How do you define 'caring' for someone who is sick?		facility
Social, cultural, and gender norms related to caretaking	• Who in this community is responsible for taking care of the sick? • What happens when someone in this community becomes sick?	Prompt: describe a recent case of a sick person, what happened	Linkage to health facilities Barriers to visiting a health facility
Leadership practices and rapport	• What is the work of local leaders, related to Ebola? • Are local leaders concerned about Ebola in your community? • Are local leaders working to prevent Ebola? • What support do local leaders need to prevent Ebola?	Prompt: describe local leaders' recent Ebola preparedness activities	Linkage with Ebola preparedness
Intra-community conflict	• Has this community had conflict within? What about with other communities? What happened? • Are most conflicts related to people's marriages, family issues, tribal issues, or what? • Does this community trust its leaders?	Prompt: describe a recent community conflict	Barriers to trust in leadership and health workers
Trust in health care workers	• What do you think of health workers? Do people have a good opinion of health workers? Can you share your problems with them? • Where do community members go first when a child is sick? What about a man/woman? • Is it easy to get to the local clinic? • Is it affordable to use the clinic?	Prompt: describe a recent case of a sick person and how it was handled Prompt: nearby clinics and which are used most Prompt: uptake of health worker advice	Health workers' delivery of Ebola messaging and community trust

Collective efficacy to prevent EVD	• Do community members come together to make decisions? • Do community members work together? • Do community members work together on Ebola?	Prompt: describe how community members have come together on Ebola	Individuals or groups who are left out or not included in community decisions
Ebola Response	• Are people aware that there is Ebola in the DRC? • Have you ever heard of a confirmed or suspected case of Ebola? • How do people respond to Ebola information? What questions do they have? • What other cultural practices might affect Ebola preparedness? • What has the government and partners done to prevent Ebola? • What challenges has Ebola preparedness presented to the community?	Prompt: sources of awareness and information Prompt: what happens if someone suspects Ebola Prompt: social, economic livelihood changes Prompt: what positive/negative changes have occurred because of Ebola preparedness	Recommendations for better community engagement and uptake of Ebola preparedness
Emic understanding of EVD messaging (PRESENT POSTER OR MESSAGE TO GROUP)	• How do you understand this message? • What can you learn? • What should be improved? • What is unclear in this message or poster?	Prompt: what do people need to know Prompt: can people change their behavior in the short-term	Recommendations for better risk communication messages

4. Key Informant Interview Guide

KEY INFORMANTS INTERVIEW GUIDE FOR STAKEHOLDERS

Study Title; "Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda"

Study Investigator: David Kaawa Mafigiri, PhD, MPH
Center for Social Sciences Research on AIDS (CeSSRA)
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P.O. Box 663 Kampala, dmk28@case.edu
Telephone number 0793371781

Version 2; 6th February 2019

KII GUIDE FOR STAKEHOLDERS

"Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda"

Interview Date: ..... **Start time:** .....

Participant ID No.: .....

Topic Focus	Core Questions	Additional Questions or Prompts	Suggested Expansion Material
Demographics and background	• How old are you? • How long have you lived in this community? • What is your ethnicity? • Where are you from originally? • How much school did you complete? • What are some of the challenges facing this community?	Prompt: issues of Ebola knowledge, preparedness, cross-border dynamics	Movement of people in and out of the community
Family history	• Where did you grow up? • What work did your parents do? • Is that similar to other work in this area?	Prompt: family dynamics and parental involvement	Closeness of the family and the community
Work history	• What work do you do and for how long? • Are there other types of work that you are doing? Are there other places you get money? • How many hours do you work per week? • Do you work every day or once in a while? How often?	Prompt: describe an average day of work	Livelihood barriers and facilitators to health-seeking behavior and Ebola preparedness
Religious beliefs	• What are some of the religions or religious beliefs in this community? Please describe each.	Prompt: describe an example of your religious beliefs and how they influence your decisions	Community religious norms and leaders

	• What do you believe? • Does your religion have any explanation for Ebola? • (As a religious leader), how do you explain Ebola - where it comes from and how it is transmitted? How do you counsel people on Ebola? • (As a religious leader), do you do any work with health workers in the area?		
Burial practices and social norms	• When someone here dies, how are they buried? How is the body prepared for burial? How is the body washed and cleaned? Who does that work? • What do people here believe about death and burials? What do you believe?	Prompt: describe a recent death and describe what happened after the person was found dead Prompt: who exactly is involved at each step of the burial	Openness to shifting burial practice based on Ebola risk
Traditional healers' understanding of EVD transmission	• How do you define Ebola? • Where does Ebola come from? • How is Ebola spread from one person to another? • Is it possible to prevent Ebola? How? • Is it possible to treat Ebola? How? • Would you refer a possible Ebola case to a health facility?	Prompt: what does your belief system say about Ebola Prompt: how would you handle someone with Ebola symptoms	Linkage to health facilities Traditional methods of treating Ebola
Caretaking practices	• Who is mostly responsible for taking care of other men, children? What about sick people and children? • Who else is involved in taking care of a sick person? Who makes decisions on when/if to go to the hospital? • How do you define 'caring' for someone who is sick?	Prompt: describe a recent case of a sick person, what happened, and who took care of that person	Linkage to health facilities Barriers to visiting a health facility
Social, cultural, and gender norms related	• Who in this community is responsible for taking care of the sick?	Prompt: describe a recent case of a sick person, what happened	Linkage to health facilities

to caretaking	• What happens when someone in this community becomes sick?		Barriers to visiting a health facility
Leadership practices and rapport	• How is your work as a leader related to Ebola? • Are you concerned about Ebola in your community? • What do you do to prevent Ebola? • What more support do you need to prevent Ebola? • Do people in the community follow your advice? If not, why and who doesn't follow the advice?	Prompt: describe your recent Ebola preparedness activities	Linkage with Ebola preparedness
Intra-community conflict	• Has this community had conflict within? What about with other communities? What happened? • Are most conflicts related to people's marriages, family issues, tribal issues, or what? • Does this community trust its leaders?	Prompt: describe a recent community conflict	Barriers to trust in leadership and health workers
Collective efficacy to prevent EVD	• Do community members come together to make decisions? • Do community members work together? • Do community members work together on Ebola?	Prompt: describe how community members have come together on Ebola	Individuals or groups who are left out or not included in community decisions
Ebola Response	• What can you share with me about your experience with Ebola from this area? • Are people aware that there is Ebola in the DRC? • Have you ever heard of a confirmed or suspected case of Ebola? • Who is responsible for Ebola preparedness and risk response	Prompt: sources of awareness and information Prompt: what happens if someone suspects Ebola	Recommendations for better community engagement and uptake of Ebola preparedness

	• How do people respond to Ebola information? What questions do they have? • How has this information changed their lives? • What challenges have you faced with Ebola preparedness and response? • What other cultural practices might affect Ebola preparedness? • What has the government and partners done to prevent Ebola? • What challenges has Ebola preparedness presented to the community?	Prompt: social, economic livelihood changes Prompt: what positive/negative changes have occurred because of Ebola preparedness	

5. Participant Observation Guide

Participant observation will involve the research team actively participating in activities done in the preparedness processes and local cultural events and meetings to inform the context of EVD. Researchers will attend stakeholder meetings for the National Task Force and coordination meetings at field sites/districts and also meetings for Ministry of Health implementing partners. This observation will inform the ways in which EVD preparedness efforts are perceived by community members. Moreover, the research team will observe activities such as market days, border crossings, festivities, local work on EVD preparedness and response, leadership and coordination meetings, cultural & religious ceremonies, health worker outreaches, and other relevant public meetings or interactions. Together, this observation will inform the social and cultural context of EVD preparedness.

As you move around the field site(s), schedule time to become familiar with your surroundings and pay attention to some of the following events, meetings, and spaces. Take notes and converse with local individuals, in order to understand the emic meaning of these cultural spaces.

	Mapping risk communication
	Posters in public places, walls, health centers
	Social mobilization efforts
	Community meetings, gatherings
	Community engagement activities focusing on themes like trust, rapport
	Sensitization meeting, preventive activities
	Screening activities, chlorination centers on the border areas
	Ebola treatment centers
	Any other Ebola preparedness and risk response activity
	Women's gender roles and caretaking responsibilities
	Religious gatherings and activities, religious spaces of importance
	Traditional and geographical spaces of importance: market days, border crossings, traditional leader meetings, cultural events and celebrations,
	Discussions of Ebola Virus Disease in public, public reaction to EVD messages

6. Research Assistants Training Agenda and Topics

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DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION

Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness in Uganda

Research Assistant Training Day 1
February 21, 2019
8 am - 4 pm

Time	**Activity**	**Responsible Person**
8:00 am - 8:30 am	Introduction and Project Objectives Overview	David & Megan
8:30 am - 9:00 am	Epidemic Preparedness in Uganda: KAP Studies and the Current Anthropological Study	UNICEF
9:00 am - 9:30 am	What is Ebola? Past Epidemics and Biological Factors.	Chelsea & UNICEF
9:30 am - 10:30 am	In the Field: Ebola Protection Kit and Protection for Field Workers	UNICEF
---	*Break*	---
11:00 am - 12:00 pm	What is Ebola? Social and Cultural Factors.	David & Megan
12:00 pm - 1:00 pm	*Lunch Break*	---
1:00 pm - 2:00 pm	Data Collection Methods & Tool Review (Observation, KII, FGD)	David & Megan
2:00 pm - 3:00 pm	Tool Review: Observation	David & Megan
3:00 pm - 3:30 pm	Tool Review: KII	David & Megan
3:30 pm - 4:00 pm	Tool Review: FGD	David & Megan
4:00 pm - 4:15 pm	Wrap Up	David & Megan

Research Assistant Training Day 2
February 22, 2019
8 am - 3 pm

Time	**Activity**	**Person Responsible**
8:00 - 8:30 am	Ethics, Confidentiality, & Privacy	David & Megan
8:30 - 9:00 am	In the Field	David & Megan
9:00 - 10:00 am	Exercise: Observations	David & Megan
-----	*Break*	----
10:30-12:00 pm	Exercise: Mock Focus Group Discussion	David & Megan
12:00 pm - 1:00 pm	*Lunch*	----
1:00 pm - 2:30 pm	Exercise: Mock Key Informant Interview	David & Megan
2:30 pm - 3:00 pm	Wrap Up	David & Megan

Elements covered during training:

- *Overview of Ebola, virology, signs and symptoms.* This included sessions led by UNICEF and study staff in order to communicate the etiology of Ebola and its signs and symptoms. A baseline working knowledge needed to be established before the study could commence, to ensure all study staff had the same level of knowledge of Ebola.
- *Detailed introduction to background and purpose of the study.* This included an in-depth presentation of the ethical considerations of the study including the principles of how to obtain the informed consent.
- *Characteristics of the study participants*. Due to the anthropological nature of the study, the RAs were sensitized on best to communicate and work with the study population.
- *Data collection tools* - Semi-structured FGD and Key Informant Interview guide. To ensure a comprehensive understanding of the interview guide, the guide was discussed in details and additional questions were discussed.
- *Qualitative research skills.* This included interviewing skills, the art of active listening, how to make the participant feel comfortable and how naturally to prompt for more details. This part further included note taking and the principles of

translating and transcribing the interviews. It also included best practices for identifying a participant was uncomfortable and what to do in challenging or unusual situations.

Exercise sessions with practicing of the study tools were conducted. The sessions consist of exercises where the RAs interview each other using the questionnaires. Simulations were conducted whereby RAs would work in pairs and conduct mock interviews. This raised areas for further clarification and follow-up discussion. This moreover served as quality assurance of both the qualitative and quantitative tools, since the RAs were able to provide feedback on the tools.

7. Extract from Code book

Codebook for Data Analysis

Category	*Sub-category*	*Code*	*Code Definition*
Health decision-making	Health sector	FIRSTCONTACT_PUBLIC	Individuals describe first going to government owned health facilities during times of illness
		FIRSTCONTACT_PRIVATE	Individuals describe first going to private owned health facilities during times of illness
		FIRSTCONTACT_TRADITIONAL	Individuals describe first going to traditional healers during times of illness
	Barriers to health seeking	1) DISTANCE_BARRIER 2) DISTANCE_NO BARRIER	Distance to clinic/health facility is mentioned as a barrier or as not an issue
		1) MONEY_BARRIER 2) MONEY_NO BARRIER	Money for clinic/health facility is mentioned as a barrier or as not an issue
		BELIEFS	Participants describe their beliefs about disease origins as a reason to not seek health care
	Trust in health workers	1) TRUST_HEALTH WORKERS 2) LOW TRUST_HEALTH WORKERS	Participants describe their trust or lack of trust in health workers
	Interactions with health workers	HEALTH WORKER_INTERACTION	Participants describe interactions with health workers
Religious beliefs	EVD Origin Beliefs	1) EVD ORIGINS_SCIENTIFIC 2) EVD ORIGINS_SPIRITUAL 3) EVD ORIGINS_OTHER	Beliefs on where Ebola comes from originally (it's a virus, it's a