

# Part 1a: Case study – Governing Ebola in Uganda

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## Introduction

Over several months of 2000 and into 2001, Uganda gained the distinction as the site of the first large scale outbreak of highly fatal Ebola Virus Disease, endemic to central Africa. Several smaller Ebola outbreaks have occurred in the country since, while at the time of the writing of this report an ongoing outbreak continues to devastate communities just over Uganda's western border, in a fragile and conflict affected part of the Democratic Republic of Congo (DRC). Indeed, such outbreaks have occurred with increasing frequency in and around Uganda, reflecting the region's continuing and even intensifying vulnerability to the virus, perhaps due to shifts in environmental, social and economic domains, and the ways in which these systems interact.

This case study considers these outbreaks, and the outbreak and epidemic preparedness of the country, in the context of this report's discussion of governance. In general, Uganda's handling of its outbreaks has been praised for being quick and effective in spite of challenges, and the country has been held up as a positive model of outbreak preparedness and response (CGHRFF & National Academy of Medicine 2016). Here, we examine the governance of these outbreaks more closely. In the first half of the report, governance of Ebola in Uganda as might be more conventionally understood – entailing formal structures, institutions, resources, norms and protocols as well as how these have changed over time – is presented. The second half of the report pivots to highlight 'alternative' perspectives on governance rooted in social science on Ebola generally and in Uganda. The aim is to make suggestions towards enhancing preparation for and handling of future emergences of Ebola in Uganda and in other low-resource contexts in more equitable and effective ways.

### *Ebola Virus Disease (EVD)*

Ebola viruses are highly infectious and virulent, with fatality rates in humans ranging from 25% to 90% depending on the species and care of patients.<sup>13</sup> They are part of a larger family of filoviruses which also includes Marburg viruses. The first known outbreaks of Ebola took place in remote villages of the DRC and Sudan in the 1970s. Another set of outbreaks in the 1990s emerged again in the DRC and Sudan, but also in Gabon and Côte d'Ivoire before hitting Uganda in 2000. Outbreaks have continued to emerge in the region and beyond, including the two recent and very large epidemics in West Africa (2014-2016) and the DRC (2018-ongoing) respectively (WHO, 2020a). Due to non-specific symptoms such as fever, weakness, cough, diarrhoea or vomiting, the disease is difficult to recognise and is routinely mistaken for more common illnesses such as malaria, thus leading to delays in its detection and response (CDC, 2015). This presents significant challenges to identifying and responding to outbreaks promptly, which is crucial to their containment. Delays are also likely as outbreaks tend to emerge in remote settings, far from essential resources.

Human outbreaks are triggered when an animal to human spill-over event occurs. Although the virus' animal reservoir(s) remain uncertain, fruit bats are highly suspected, with other wild forest animals including non-human primates being intermittent carriers (WHO 2020). Initial human infections are caused by contact with fluids or secretions of infected animals, which can then trigger chains of human to human transmission within communities as people come into contact with one another, such as during caring or funerary activities or in hospitals (Francesconi et al., 2003). There is no effective treatment for Ebola, but supportive care in the form of hydration and symptom management can improve survival rates (Kadanali & Karagoz, 2015). A vaccine trialled during the West African epidemic and now being used in the DRC and surrounding countries appears to show promise in protecting against infection (WHO, 2020a).

To date, Uganda has experienced six outbreaks of Ebola which are briefly described below.

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<sup>1</sup> There are five known species of Ebola, four of which are known to infect humans

All but one of these outbreaks were caused by the Sudan strain of the virus. Although it has a fatality rate ranging from 40%-60%, it is less deadly than *Zaire ebolavirus* which tore through West Africa in 2014-2016 (and is now transmitting in DRC) and has a fatality rate of 60-90% (Kadanali & Karagoz, 2015).

### **2000-2001, Gulu district, northern Uganda**

The 'Gulu' outbreak was the largest Ebola outbreak to have occurred at the time and was the first known one in Uganda. A total of 425 people across three districts were infected with the *Sudan ebolavirus* and 53% of them, including 17 health workers, lost their lives over a period of six months. The outbreak began and hit hardest in the conflict-affected northern district of Gulu (393 cases), and spread to rural Masindi and Mbarara districts to the south (Okware, 2015). Unlike previous known outbreaks which had been confined to remote settings, this outbreak spread from peripheral villages into the comparably 'urban' environment of Gulu Municipality, and into camps for internally displaced persons (Okware et al., 2015). Its initial emergence was never determined and, indeed, the virus itself was not recognised as Ebola for approximately 6 weeks of circulating in villages as a 'mysterious' illness. It was only after a cluster of health workers died after being infected at Lacor Hospital that the district head of health services reported to the Ministry of Health (MOH), who subsequently arranged to have a sample tested in a WHO reference laboratory in South Africa where it was later confirmed to be Ebola. Both in-hospital and community-based transmission occurred, with many instances of the latter being associated with home care and funerary practices, and the former with inadequate information and resources for isolation and barrier nursing practices in hospital. Response from both formal national and international institutions implementing standard Ebola control strategies and informal local community responses successfully contained the outbreak.

The outbreak reached Masindi district, 170km south of Gulu, when a woman from the area returned from Gulu after 'escaping' Lacor Hospital with an infection acquired while being treated there for a chronic condition. The virus spread to 18 members of her extended family and six healthcare workers. The initially high fatality rate reduced after isolation and barrier nursing techniques were improved (Borchert et al., 2011). Community-imposed quarantine upon the affected family, which was of Kenyan origin, has been widely credited with its containment as was the coordinated formal response. An infection in a soldier in Mbarara, 500km south of Gulu, resulted in four additional infections, all within the army. The outbreak did not spread out of the military barracks into the community (Kinsman, 2012).

### **2007-2008, Bundibugyo district, western Uganda**

Emerging in a mountainous rural region of western Uganda bordering the DRC, the Bundibugyo outbreak lasted six months. It had been caused by a new species of Ebola virus, identification of which lagged three months behind the verification of an outbreak. The *Bundibugyo ebolavirus*, as it was named, proved less deadly than the Sudan strain, killing 34% of the 116 cases. Initial zoonotic spill-over is thought to have occurred possibly through hunting activities in the area's national parks, but this was never verified as such hunting is illegal and community members claimed not to engage in such practices (Wamala et al., 2010). Most transmission occurred within the community through care and funerary practices, including relating to the death of a high-status local leader which contributed to a large proportion of infections, although nosocomial transmission was also a factor (MacNeil et al., 2011; Okware, 2015). Once the outbreak was confirmed as Ebola, it was contained within three weeks after a more formal and concerted response was mounted. Following this outbreak and with support from the US Center for Disease Control (CDC), a laboratory in Entebbe was upgraded with the capacity to verify Ebola so that samples would no longer have to be flown abroad (Callaway, 2012).

## **2011, Luwero district**

In May, a report was made to the MOH of a 12-year-old girl presenting to clinic with a suspected filovirus in a village 50 miles north of Kampala. Unfortunately, the young girl died shortly after being hospitalised, isolated and cared for by nurses and physicians who took precautions against suspected Ebola, and the outbreak did not spread beyond her (Shoemaker et al., 2018). The girl's infection was verified by the new laboratory facilities at Entebbe and, when confirmed, a team was dispatched to her village to contact and support anyone exposed the following day (Callaway, 2012). Health workers' initial suspicion of Ebola, the country's new laboratory facilities, and the prompt response after confirmation are credited with the limited nature of this outbreak.

## **2012, Kibaale**

Another outbreak occurred in Kibaale, a district on Uganda's western border with the DRC. A teenage girl is thought to have contracted it while undertaking agricultural work in a forested area. Several relatives who cared for and buried her, along with the funeral priest, a health worker and a few others also contracted the disease and/or passed away, making for a total of 24 cases and 17 deaths (Okware, 2016). After confirmation of Ebola at the lab facilities at Entebbe, a formal response was launched within two days (Aceng, 2015).

## **2012, Luwero district**

A second outbreak in Luwero district erupted just as the Kibaale outbreak came to a close, although it was ultimately smaller with only seven cases and four deaths. The first person suspected to have been infected was a motorcycle taxi driver who may have been infected by a passenger. He was treated for malaria, but after worsening and being sent to Bomba Military Hospital he passed away. His body was given to his relatives who subsequently buried him in the customary way. Two of his sisters subsequently developed symptoms and went to a clinic where they too were treated for malaria. When it was revealed their brother had recently died after experiencing similar symptoms, the clinic director contacted the Ministry of Health. Although response from the national level was relatively late, including in confirming cases at the national lab, the outbreak was confined to seven members of the same family (de Vries et al., 2016; Nkonwa, 2015).

## **2019, Kasese district**

Two separate 'imported' cases of Ebola occurred in Kasese district which borders the DRC, where a protracted Ebola epidemic had been ongoing. A five-year-old boy and a nine-year-old girl were brought by family members from the DRC in June and August respectively to seek treatment in Uganda. Both were sent to an Ebola Treatment Unit at Bwera Hospital. Unfortunately, both also passed away as did the grandmother and brother of the young boy. No further cases occurred, and known contacts were tracked down and vaccinated.

## **Ebola: What's the problem?**

The presentation of any Ebola outbreak as mostly the sum of its epidemiological dimensions – location, origin, transmission, spread and containment – is a typical formula for imparting information about it. And while this is useful for researchers, policy makers and practitioners considering how to prevent, slow and stop outbreaks, it also reflects a particular framing and understanding of what the problem is. As suggested in the overarching report, by identifying and deconstructing dominant narratives and framings around outbreaks of disease, critical scholars have revealed how what is considered to be the problem by those with discursive and material power has implications for the ways in which strategies and resources are deployed to tackle it (Leach & Dry, 2010). These framings, and the strategies they legitimate, are reflected in formal governance relations, goals and activities.

There are two overlapping and interrelated dominant framings of the problem of Ebola in Uganda. The first locates Ebola as a disease which emerges in remote and exotic corners of Africa, and yet, because of its virulence and the perceived ease with which it can be transmitted between people, has the potential to threaten the entire world (Leach & Hewlett, 2010). In this 'outbreak narrative', which is particularly entrenched in Euro-American popular culture, the problem is emphasised to be Ebola's potential to spread and threaten wealthy countries in particular, either via ever more complex and dense networks of global travel and commerce, or through its intentional release as a weapon of bioterrorism (Polesky & Bhatia, 2003; Wald, 2007). This fear of global Ebola spread and the need for 'global health security' are credited with some of the political momentum behind the WHO's new orientation at the turn of the century to stronger international disease surveillance, preparedness and rapid response, the establishment of 'core capacities' with which member states must comply, and for the creation of the GOARN to support this (Leach & Hewlett 2010, p. 55).

Institutionalised in the WHO's International Health Regulations (IHR) (2005), these objectives frame problem constructions and governance for Ebola at the national level in WHO member states. In Uganda for example, the MOH's Multi-hazard Preparedness and Response Plan for Public Health Threats and Emergencies states the need to 'identify and address the gaps and accelerate Uganda's progress towards achieving the International Health Regulations (2005) core capacities' (Uganda MOH, n.d.a p. i). The fast spreading and international reach of the West African Ebola epidemic injected renewed urgency into the international global health community and thus, at least rhetorically, among many national actors for improving core capacities.

While it is nested within the above broader framing and influenced by the objectives of global health actors and the IHR, it is a second narrative which has prevailed in the discourse of actors most influential in addressing Ebola in Uganda and in producing knowledge about it, which is most reflected in formal governance structures, objectives and strategies, particularly at the national level. This narrative positions the virus and its emergence as a more localised public health threat and emphasises the country's unique vulnerability to the disease, which it considers to be a 'high risk' (Uganda MOH, n.d.a). This is not only because Ebola is endemic in Uganda, but also because outbreaks in neighbouring countries such as the DRC – which suffers from political instability and weak institutions (Li & Young, 2013) – have the potential to 'spill over' into Uganda (UNICEF, 2019). While a similar formula of surveillance, prompt detection and rapid technical containment strategies is seen as essential for preventing and tackling Ebola at the local level, this narrative primarily frames these activities as necessary for limiting mortality and tragedy in communities and within countries (Leach & Hewlett, 2010). In framing these technical activities as the cornerstones of successful Ebola prevention and response, both dominant narratives privilege biomedical and epidemiological problem framings and action around Ebola, and legitimate mostly top-down preparation and protocols. Local people in affected communities are usually framed as needing to be educated in the biomedical model of Ebola, and trained or convinced to cooperate and 'accept' the response. Thus, 'social mobilisation', 'sensitisation' and extensive communication with communities through various channels including media and local leaders is also articulated as necessary and crucial to successful control in Uganda. Local belief in rumours and witchcraft which can 'obscure the viral nature of the disease' (Muyembe-Tamfum et al., 2012, p. 7), along with traditional social and spiritual practices, especially in the context of death rites and burial, are often framed as problems which must and can be overcome through these strategies (Li & Jones, 2014).

## **Context and complexities**

Although a more or less standard set of capacities, protocols and procedures for outbreak preparedness and response activities exists in the form of the IHR and various other norm setting devices and incentives at the international level, outbreaks emerge and occur in

specific contexts with unique social, economic, political, cultural and ecological dynamics which interact in different ways to influence when, where, how and among whom Ebola might spill over and spread, as well as how preparedness and response unfold. This section gives a brief overview of Uganda, with special attention to some of the contextual specificities of the country which influence these processes.

Landlocked and sharing borders with five other countries, including South Sudan to the north and the DRC to the west, Uganda is an equatorial country in the Great Lakes region of East Africa with a population of approximately 43 million. Although the country has been under a free market system since 1987, at just \$620 GNI per capita (current USD) and with 41.7% of people earning under \$1.90 a day (up 6% since 2012), Uganda remains one of the poorest countries in the world (World Bank, 2019). Although urbanisation has been occurring at an increasing pace, most of the population lives in rural areas and undertakes subsistence agriculture (UBOS, 2014). Increased pressure on land due to demarcation of land for national parks has occurred in some areas, particularly in some western regions (Ryan, 2018). The country is marked by persistent and even widening inter-regional inequalities, with central and western regions having developed more quickly than eastern and northern areas, the latter of which also experienced a period of protracted conflict (World Bank, 2016). The country ranks 159<sup>th</sup> out of 189 countries in the UNDP human development index, which takes into account life expectancy, access to knowledge and standard of living, putting it in the 'low human development group'. Despite this, the country has made some progress between 1990 and 2018, with life expectancy having risen from 46 to 63 years, and an increase in mean years of schooling from 2.8 to 6.1 years (UNDP, 2019).

Reflecting Uganda's early history, the country remains divided generally along cultural and linguistic lines, with Bantu speaking peoples residing in the more affluent south and west and Nilotic speaking peoples in the north. During a 67-year period of colonial rule from 1894 to 1961, British colonisers exploited these already existing regional and economic cultural fault lines, and deepened interregional inequalities which are still felt today (Mutibwa, 1992). A period of political and economic instability followed Uganda's independence in 1961, during which two coups were carried out. The latter of these was led by Yoweri Museveni in 1986, who has remained as Uganda's president ever since, having been re-elected several times and most recently in 2016. Although charges of corruption have been consistently made against him, and perceived political neglect in the north had fuelled violent rebel groups there until recently, Museveni has governed over a period of relative political stability. This stability has allowed for the development of strong governance institutions at the national level which have been credited with the country's comparative success in handling outbreaks of Ebola *vis-à-vis*, for instance, the DRC or Sierra Leone, even in the conflict affected and infrastructurally deteriorated north (Li & Young, 2013; McPake et al., 2015). Today, Uganda is an active participant in international bodies including the East Africa Community, the African Union and the UN, and has an active military presence across the continent.

## Health system

The Ugandan constitution recognises health as a human right, and health system development has been a priority in the country, with achievement of universal health coverage a goal of the country's national development plans and a number of strategic plans and policy guidelines for health having been developed. That said, as is the case with many countries in sub-Saharan Africa, Uganda embarked upon a path of market reforms in the 1990s, pulling back from and decentralising its health system. Although some notable health achievements have been made since, including reductions in under-five and maternal mortality, this restructuring and the resultant decrease in investment in public health services is noted by some as even having led to a reduction in quality and access to basic care, particularly in the two decades following reform (Calain, 2007; Pfeiffer & Chapman, 2010).

Public sector and private sector services each account for about half of total services

respectively, with much of the latter being run by not-for-profit religious organisations in partnership with the state (Uganda MOH et al., 2012). The system is decentralised and organised in tiers, with Village Health Teams (VHTs) at the foundation and a graded system of health facilities at the various levels of a district, up through which referrals may be made. District administrations are responsible for planning, implementing and monitoring health services and activities at these subordinate levels, and for communicating and cooperating with the national administration and hospitals at higher levels.

### **Challenges and realities**

Despite the clear vision for a neatly tiered and accordingly provisioned health system, the reality is quite different. Although fees for health services were abolished in 2001, patients are routinely expected to pay informal fees or purchase medicines from private pharmacies due to clinic stock outs (Nkonwa, 2015; Xu et al., 2006). In rural areas in particular, formal health services may not only be hard to get to, but are frequently under-resourced and severely understaffed (Musoke et al., 2015). Uganda has a doctor to population ratio of one to 25,000 and a nurse to population ratio of one to 4,000 (Okware, 2016). This has often been attributed to the difficulty of recruitment given poor salaries and incentives. Understaffing is also a problem at the national level, as up to 51% of approved posts have been reported to go vacant due to inadequate funding (Okware, 2015).

In this environment of severe shortages, Uganda must contend with a high disease burden and the added pressure of several hundred thousand refugees from neighbouring countries experiencing conflict. Although significant progress has been made in relation to reductions of infectious diseases such as HIV and TB, new infections of which have declined significantly, communicable diseases including malaria, pneumonia, diarrhoea and respiratory infections continue to place significant burden on the country (Uganda MOH, 2016).

### **Governing Ebola in Uganda**

As already suggested, formal governance of Ebola outbreaks in Uganda has been and continues to be influenced by agendas, actors, instruments and incentives at the global level. This influence is reflected in national and subnational structures and arrangements. This section maps out these governance arrangements to present the view of how global health and national actors envision Ebola should be tackled in Uganda.

#### **Global and regional governance for Ebola**

The Ebola outbreaks that have occurred in Uganda over the course of the last two decades have transpired alongside major shifts in global health governance, including, specifically, in the realm of infectious threats. These shifts, outlined in more detail in the overarching report, included reform of the legally binding IHRs, obligating all member states of the WHO to develop 'core capacities' to 'prevent, protect against, control and provide a public health response to the international spread of disease' for 'global health security' in the context of a rapidly globalising world (WHO, 2008, p. 1). As already mentioned, these obligations are strongly oriented towards surveillance and obligate states to build up their capacities to detect serious diseases such as Ebola, and, when they do so, to inform the WHO within 24 hours. The national government may then request WHO's support in mounting a rapid response which it does through mobilisation of members of the GOARN and other networks. If the threat is determined to be a public health emergency of international concern (PHEIC), a broader international response will be mobilised.

None of the outbreaks in Uganda - apart from the recent isolated cases of people crossing the border from the DRC with infections - have been considered PHEICs, although the WHO has supported the national government in responding to several outbreaks, including the first and largest in Uganda in 2000-2001 (at which time the designation of PHEIC did not exist). With support from the WHO country office, a suspected sample was sent to a WHO reference

laboratory in South Africa. After the disease was confirmed to be Ebola, the national government made its formal request to WHO for support, which subsequently mobilised two dozen different international member organisations of the GOARN who contributed funding, expertise and on-the-ground implementation (WHO, 2001). The CDC, for instance, set up a mobile laboratory at Lacor Hospital capable of diagnosing Ebola, and thus precluding the need for samples to be sent abroad to confirm cases. This has been framed as a key measure in the response at Gulu as it allowed for prompt case confirmation and thus timely treatment and separation of confirmed from non-cases (Lamunu et al., 2004).

In the context of emergencies, global support for outbreak governance also ramps up for neighbouring and at-risk countries. In light of the ongoing outbreak in the DRC for instance – the world's second largest so far and declared a PHEIC by the WHO in July of 2019 – the WHO published the Regional Strategic EVD Readiness Preparedness Plan in Countries Neighbouring the Democratic Republic of Congo, identifying gaps and areas in urgent need of reinforcement based on recommendations from Preparedness Support Team missions, results of EVD Preparedness checklists and Joint External Evaluations (JEE) (WHO-AFRO, 2018). The plan provides 'a framework for collaboration and coordination for on-going and planned partner activities aligning towards the central purpose of establishing operational readiness' (p. 4). More recently, the United Nations Children's Fund (UNICEF) has published the Regional Outbreak Preparedness Overview of Needs and Requirements based on the national preparedness plans of countries considered at risk of receiving imported cases. 'Priority 1 countries' such as Uganda are urged to work with partners to improve detection and case management preparedness, assess and equip health facilities and staff, monitor population movements, deploy risk communication and community engagement and approve experimental medicines and vaccines (UNICEF, 2019). Such plans reinforce global governance commitments and objectives as laid out in the legally binding IHRs and numerous other 'soft' strategies, plans and initiatives at global, regional and national level. These priorities are also reflected in formal national-level governance.

## **National and sub-national governance**

Despite the surprise of Ebola in northern Uganda, the outbreak's unprecedented scale, and the complex context beset by crumbling infrastructure and protracted conflict into which it emerged, the response of the national government has generally been lauded. While there has been some evolution of the national and sub-national governance architecture and related functions and objectives, the basic formula for preventing and tackling EVD in Uganda has mostly remained in place since. The Gulu outbreak has been extensively documented by a number of authors, including some directly involved in the response (Kinsman, 2012; Lamunu et al., 2004; Mbonye et al., 2014; Okware, 2016; Okware et al., 2002; Omaswa et al., 2015). This makes it an ideal case to present a picture of what formal governance for Ebola in Uganda looks like in action. The following attempts to patch together such a picture, based on the collective descriptions of the authors cited above, in addition to documenting shifts and changes to governance structures and priorities over time, including in both outbreak and non-outbreak periods.

## **Governing in Gulu**

A six-week delay between the first cases and the notification of the MOH and mobilisation of a formal coordinated response in Gulu in 2000 reflects a number of factors, including the inherent difficulty of recognising the disease, the fact that it had never before been formally detected and managed in Uganda, and local contextual specificities. The area, politically neglected and long under siege by rebel groups who terrorised and forced local populations into refugee camps, was suffering from a severely deteriorating health system and general infrastructure (Accorsi et al., 2005; Okware et al., 2015). Earlier the same year, however, Uganda had been one of the first African countries to adopt the Integrated Disease Surveillance and Response (IDSR) strategy developed by the WHO and CDC and embraced

by WHO-AFRO (WHO, 2003).<sup>24</sup> The IDSR entails a decentralised surveillance system linked to the country's Health Management Information System (HMIS), through which trained health workers at any level (including village level teams) can investigate and report suspected or confirmed cases of notifiable diseases to focal points, who feed these up through the system to facilitate early detection and to trigger coordinated response when necessary (Mbonye et al., 2014).

A day after receiving the reports of a mysterious illness from Gulu district on the 8<sup>th</sup> October through the IDSR framework, the Ministry of Health (MOH) sent a team to verify that an outbreak was underway. The team investigated cases, collected and sent samples for testing, established rudimentary active surveillance and recommended the immediate establishment of isolation facilities outside Lacor Hospital on October 10<sup>th</sup>. After re-verification of the outbreak with support from a new team including personnel from the country's WHO office, a National Taskforce (NTF) in the MOH and answerable to the Office of the Prime Minister was formed on October 12<sup>th</sup>. A national level Inter-ministerial Taskforce (IMT) was also established to 'provide political direction', especially on issues relating to trade and tourism (Okware et al., 2002). The same day, a limited amount of personal protective equipment (PPE) for barrier nursing was issued to the isolation facility. Although the formal response was already underway in Gulu following the investigations of the MOH and WHO country officials, confirmation of Ebola virus disease on October 14<sup>th</sup> from the National Institute of Virology in South Africa triggered the issuing of an 'Alert' to all districts across the country, and spurred the MOH to make its formal request to WHO to coordinate an international response.

Mirroring the NTF and closely monitored by it, District Taskforces (DTF) comprised of district health, civic and political leadership were set up in districts across the country, with the Gulu DTF obviously being of most significance at the time (although trainings were conducted with personnel from surrounding districts in anticipation of possible spread). Working closely together and meeting daily during the outbreak, the NTF, DTF and their various subcommittees took on the task of coordination and logistics to implement response alongside 100 foreign experts brought in by the WHO via the GOARN. Rapid Response Teams (RRTs) at district level, whose roles entailed the monitoring and support of response activities and 'verification of rumours' were also set up. Sub-district structures for response coordination were established at county, sub-county, parish and village level to support and carry out activities. Reflecting sub-committees of the NTF and DTFs, response activities are usually described in this and other outbreaks as falling under the domains of coordination and logistics (NTF, DTF and RRTs), surveillance, laboratory screening, case management, social mobilisation, and, later, psychosocial support.

#### *Active surveillance and contact tracing*

To detect, isolate and initiate care for infected people as early as possible, active surveillance at Gulu was established. This entailed recruiting and training 'scouts' and village leaders to actively search for possible 'alert' cases. Trained mobile teams would then follow up and dismiss or escalate cases as 'suspect' and alert an ambulance team to transport these patients to an isolation unit where further assessment would be undertaken by medical personnel, and where infected individuals would be cared for. These mobile teams, comprised of a cadre of 160 trained volunteers, also tracked deaths, alerted burial teams as necessary, and conducted contact tracing and monitoring. Because Gulu was the site of a protracted conflict, responders had to be escorted by armed personnel when traveling around the district, and one scout was killed by rebels (Kinsman, 2012).

#### *Laboratory screening*

At the time of the Gulu outbreak, Uganda had no in-country laboratory which could process

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<sup>2</sup> As IDSR precedes the 2005 reformed IHR, African WHO member states have recommended that expectations for IHR compliance be made within the context of IDSR (Uganda MOH, n.d.b).

and confirm samples; thus, the earliest samples were flown to the WHO reference lab in South Africa. However, the CDC, as part of the international response, set up a mobile lab on the premises of Lacor Hospital allowing samples to be tested on-site. This is frequently framed as a key measure in helping to contain the outbreak as cases could be confirmed relatively quickly (Lamunu et al., 2004).

### *Case management*

Activities in this area included the establishment of isolation units at Lacor and other hospitals (Gulu Regional as well as at hospitals in Masindi and Mbarara districts when the outbreak reached these locations), training and support of health workers for barrier nursing techniques and infection control protocols, and provisioning and training for the use of PPE among relevant response actors including clinical personnel and others such as burial teams, who had to be recruited and further trained to perform safe burial.

### *Social mobilisation and community education*

Social mobilisation is usually described as consisting of education and public messaging through media such as radio, television, film screenings, and posters and billboards, but also live music and local drama. Village Health Teams and other volunteers were also engaged to go door-to-door with information. Thus, the focus here tends to be on one-way provision of information from response actors to communities who must be educated or convinced to comply with, believe in, or 'accept' the response and the reality of Ebola (Muyembe-Tamfum et al., 2012). Social practices such as swapping handshakes for elbow bumps, community-imposed quarantine of infected individuals as occurred at Masindi district, and even eventual agreement from the rebels to 'cooperate' with the response, have been cited as evidence of the success of social mobilisation during this outbreak. Traditional healers were banned from practicing at Gulu, while the identification of customary burial practices as a route of transmission also led to a ban on these practices among people.

## **Explaining success**

As suggested above, the response at Gulu is generally framed as having been a success, and lessons from this outbreak and from Uganda generally have frequently been evoked in the context of thinking about and responding to outbreaks in other countries. This success is often framed as a matter of good governance in the sense that Uganda had an operational health policy and strategic plan in place, which included surveillance and control for notifiable diseases across a decentralised system with political support behind it, and during the outbreak authorities were able to take decisive action and effectively coordinate across district, national and international levels – inviting the participation of the WHO early on, for instance – to implement key containment measures (CGHRFF & National Academy of Medicine, 2016; Maurice, 2000; Mbonye et al., 2014).

## **An enduring framework**

Although the success of the response at Gulu can be attributed to a number of factors (including community responses which are discussed later in this report), the basic governance architecture for health emergencies, including the structures of the NTF and DTFs, along with the above domains of response, have largely endured. Accounts of subsequent outbreaks have traced similar stories, from reporting via surveillance architecture at the local level to the MOH's Epidemiology and Surveillance Division, through to national, international, district and sub-district coordination and mobilisation of resources, staff, systems and protocols in the race to contain the outbreak. Some shifts in formal response have occurred over the years, including the addition of a new psychosocial support domain to response which entails working with communities to understand their 'misconceptions', design socially acceptable solutions, as well as counsel patients and health workers (Mbonye et al., 2014). In addition to in-outbreak response, improving preparedness and surveillance during non-outbreak periods has been a major theme in Uganda's governance for Ebola outbreaks.

Notable efforts to build on this over the years have included the establishment of an Emergency Operations Centre (EOC) in 2013 – a facility equipped with communications and information technology from which to coordinate emergency response – and a specialised surveillance program for Ebola and other filoviruses, both established with support from the CDC (Borchert et al., 2014).

A series of plans, strategies and guidelines have been developed over the years which reinforce these formal structures and governance priorities as well as clarify their roles and functions, including, most recently, the National Multi-hazard Preparedness and Response Plan for Public Health Threats and Emergencies 2016-2020 (MPRP). The relevant objectives of the plan are threefold: 1) to 'prevent and reduce the likelihood of disease outbreaks and other public health hazards'; 2) 'to build the country's capacity to detect public health threats early'; and 3) to 'guide a coordinated, rapid, effective and multi-sectoral response to public health hazards' (Uganda MOH, n.d.a, p. 1). Seemingly in response to the West African outbreak and supported by WHO and DFID, the MOH published standard operating procedures for responding to Ebola and Marburg outbreaks in 2015 (Uganda MOH, 2015). Both of these appear to more closely align health emergency personnel and policy with disaster management policy and actors. Mass trainings for health workers, communities and immigration officers in border districts were also undertaken at this time (Bazeyo et al., 2015).

## **Challenges, gaps and enhancements**

While the outbreak response and containment at Gulu is generally considered to have been successful, this experience did reveal gaps and yield lessons for Uganda, as have subsequent outbreaks in the country. From a formal governance and public health perspective, these lessons are generally framed as technical issues around the speed with which Ebola is recognised and reported in the community, confirmed by experts, and effective response at multiple levels coordinated and implemented.

### **Recognition and reporting: improving surveillance**

As already mentioned, six weeks went by between the onset of symptoms in the first case of Ebola in a rural village outside of Gulu and the reporting of an unusual illness by district authorities to the MOH. Lamunu and colleagues (2004) attributed this delay to several possible factors. Firstly, it was the first outbreak of EVD to have occurred in Uganda and, because of this, health workers would not have been expecting to encounter such a disease. Secondly, its non-specific symptoms are often attributed to more common infections such as malaria or, among communities, witchcraft (Polonsky et al., 2014). Thirdly, traditional healers are not integrated into formal surveillance systems, even though many Ugandans seek care from them. Identifying the problem as a matter of early detection thus frames the improvement of surveillance systems to be an appropriate solution. The government has responded to this by introducing standard clinical and community case definitions for recognition of EVD, including training for application of these by VHTs at the lowest community level (Mbonye et al., 2014). Training for other health workers and relevant actors at district level to enhance surveillance, such as members of DTFs and RRTs, has also been a priority over the years (ibid.). This has been stepped up in the context of outbreaks of EVD in other countries, such as the West African outbreak of 2014-2016 and the ongoing outbreak in DRC, when targeted media campaigns and trainings for health and immigration workers in strategic areas were carried out (Bazeyo et al., 2015; Uganda MOH, 2019). In 2012, Uganda became the second LMIC to adopt District Health Information Software 2 (DHIS2), a digital open source health data management platform (Open Health News, 2016). Integration of surveillance activities with the DHIS2, including the introduction of SMS reporting, is credited with improved completeness and timeliness of disease reporting generally (Masiira et al., 2019), while the addition of an outbreak response module to the platform in 2013 with CDC support represents another technical advance (Borchert et al., 2014). It has been noted that

an increased frequency with which outbreaks seemed to occur, especially between 2007 to 2012, might actually have been the result of improvements in surveillance rather than any actual increase (Polonsky et al., 2014). That said, delays in detection are a continued concern, continuing to prompt calls for training to rural medical personnel (MacNeil et al., 2011).

### **Laboratory capacity**

A major area of investment for the Ugandan government and its international partners has been the upgrading and improvement of laboratory capacity for testing EVD and other filoviruses in the country. In the Gulu outbreak, confirmation of Ebola was made only after a sample was flown to a South African WHO reference lab. A long delay between investigations and confirmation was experienced at Bundibugyo, a mountainous rural district in western Uganda where a mysterious illness had been circulating since August of 2007. Early cases were reported through surveillance networks and subsequently tested in-country with inconclusive results. Following a cluster of 20 deaths, including health workers, samples were finally flown to the CDC in Atlanta for advanced analysis. A new strain of EVD was identified in late November, three months after initial investigations began (Okware, 2015).

Transmission in the community occurred throughout this long period, mostly via caring and burial activities, but was contained within three weeks following a deployment of formal response following confirmation. In total, 116 people were infected and 39 died. This experience prompted renewed calls to improve laboratory capacity in the country, which in 2010, and with assistance from the CDC, led to the establishment of filovirus testing facilities at the Uganda Virus Research Institute (UVRI) and enhancement of general technical filovirus surveillance capabilities (Callaway, 2012; MacNeil et al., 2011). The lab has successfully confirmed over a dozen filovirus outbreaks (including of Marburg) with a turnaround time of under 24 hours, thus enabling prompt responses (Mbonye et al., 2014; Shoemaker et al., 2018). This and other programmes for surveillance enhancement have also focused on training health workers at various levels on filovirus surveillance and response activities, including identification of possible cases, infection control protocols, sample collection, packaging and shipping (Borchert et al., 2014).

### **Preparedness and response**

In addition to efforts made to train health workers on how to recognise the disease, and stepping up laboratory and technical facilities and capacities for quick transport and testing, efforts have also been made to enhance general preparedness. To ensure readiness, the NTF, which first swung into action during the Gulu outbreak, remains a standing body even during non-outbreak periods when it goes from daily meetings during outbreaks to monthly or quarterly meetings (Aceng, 2015). DTFs and other disaster response structures at district level are also encouraged to undertake measures during non-outbreak periods. This includes coordinating emergency training for communities and health workers, supporting stockpiling of supplies for emergency response, designing community communications plans, conducting emergency response simulation activities and more (Uganda MOH, 2015). The extent to which these activities actually occur at community level is unclear. Preparedness activities such as simulation exercises have also been conducted at the national level. For instance, Uganda was the site of a six-month long 'global health security demonstration project' directed by the CDC in collaboration with the MOH in 2013 (Borchert et al., 2014). Seventeen out of the country's 112 districts were selected to undergo 'rapid capacity building' and 'drills' conducted with the support of US military forces. The project culminated in assessments showing improvements in specimen referral and outbreak communication systems.

Additionally, because of its 'fully operational and state-of-the-art' Public Health Emergency Operating Centre (EOC), operational emergency response plans and experience in this area, Uganda was supported by the WHO to host a training for health leaders across sub-Saharan Africa on simulations (WHO-AFRO, n.d.).

Another priority area of preparedness aimed at lower levels has been the enhancement and institutionalisation of 'rigorous procedures to control cross-infection' in clinical settings (Cohen, 2004). At Gulu, 64% of the healthcare workers infected during the outbreak acquired EVD *after* isolation and barrier techniques were adopted, thus demonstrating the need for greater health worker support in terms of training and resources. Improvements to address this have included the adoption of a 'buddy' system in which pairs of health workers monitor each other's compliance to safety procedures (Borchert et al., 2011). Although a general lack of resources and supplies at health centre level continue to be acknowledged as an ongoing and persistent challenge, it is less clear to what extent systematic assessments of the gaps in this area at health centre level for emergency response have been made, and what efforts have been made to alleviate these. Individual examples, such as infrastructural improvements to and adoption of infection control protocols in Gulu's Lacor Hospital have been described (Lamunu et al., 2004), but lower level health centres appear to suffer from a lack of sustainable supplies for emergency response (Nkonwa, 2015). Although it is claimed that 240 health workers had been trained in 'epidemic preparedness and response' in Uganda's western region in the most recent health system progress report (to prepare for outbreak spill-over from the DRC), it is not clear whether adequate resources have been provided such as PPE (Uganda MOH, 2017). That said, later outbreaks of EVD have mostly precluded health worker infections, at least after isolation and barrier nursing techniques have been instituted.

Despite serious resource challenges, Uganda's progress in terms of the 'core capacities' of the IHR exceeds that of most other countries in the region. Presenting assessments of countries' epidemic preparedness and response capacities in the context of the ongoing EVD outbreak in DRC, Uganda scores 50%, second only to Rwanda with 60% (WHO-AFRO, 2018). One theme that comes up in discussions of Uganda's comparable success in this area is political will. Since the adoption of the IDSR through to the various efforts it has made to enhance surveillance and response, the Ugandan government has been praised for its commitment in this area (Polonsky et al., 2014; WHO, 2003).

### **Additional challenges and gaps**

Although Uganda has clearly made moves towards shoring up gaps in preparedness and response, deep structural challenges, common to many LMICs, remain. The country's most recent Annual Health System Progress Review (2017/2018) illustrates how the health system remains chronically underfunded. Staff shortages are endemic at all levels (including in the national Epidemiology and Surveillance Department), and stockouts of essential medicines and supplies, as well as maintenance of existing medical and infrastructural equipment, remain challenges. Per capita public health expenditure remains substantially below the minimum recommendation for low-income countries. Access to formal health system remains patchy in some areas, especially more rural and vulnerable parts of the country. Services are further strained in areas hosting large refugee populations from neighbouring countries (Uganda MOH, 2017). The recruitment and retention of health workers has been framed as a constant difficulty both in terms of basic salaries and general conditions (Okware, 2016), but also in terms of the exceptional circumstances of outbreaks (Borchert et al., 2011). Health worker fatigue, exhaustion, and even fleeing have been serious problems during EVD outbreaks. Despite all the trainings and preparedness exercises, few health workers have actually experienced managing EVD outbreaks, and thus those that do are often sent to outbreak sites when they occur (Nkonwa, 2015; Okware, 2015). Many of these challenges are common to countries across Africa and LMICs elsewhere, and addressing them requires the mobilisation of external support. Improvement of general pay and conditions, as well as psychological and social support, and risk allowance and compensation for outbreak workers and their families is framed as an important measure, and examples of this in the past are credited with improved response (Okware, 2016).

## Key stakeholders and influential parties

### Formal actors

The governance structures and response activities described above very much reflect the priorities and protocols for EVD and other epidemic-prone disease preparedness and response promoted by global health actors such as the WHO and CDC. The significant role played by these actors in influencing Uganda's early surveillance and response plans and activities, through the adoption of the IDSR, is testament to their long-term influence.

Ongoing influence in policy, governance and implementation for preparedness and response is evident across much of Uganda's continuing policy development and implementation, such as in the establishment of the EOC, upgrading of laboratory capacities for filovirus testing, and Uganda's early adoption of GOARN developed digital outbreak investigation software (Bazeyo et al., 2015; Callaway, 2012; WHO-AFRO, 2019). During actual response, other international actors, such as organisations and agencies of the GOARN, reinforce the importance of the technical domains of response, further institutionalising standard ways of implementing these.

Despite Uganda's decentralised health system structure, power to mobilise necessary resources for Ebola response is highly centralised as district and sub-district level health facilities operate on shoestring budgets, and frequently go without essential supplies (Nkonwa, 2015). The Ugandan MOH is responsible for public health related emergencies, including through the aforementioned NTF and its technical sub-committees, which are comprised of experts from the MOH's various departments and divisions and other relevant ministries and authorities such as the Ministries of Agriculture and Education and the Uganda Wildlife Authority, as well as members of the armed services, Office of the Prime Minister and partner organisations including research institutions and universities and global and domestic organisations such as the WHO, CDC, UNICEF, AFENET, the Ugandan Red Cross and Médecins Sans Frontières (MSF) (Aceng, 2015; Mbonye et al., 2014). More specifically, these actors are reported to be a mix of laboratory scientists, epidemiologists, physicians, psychologists, veterinarians, health communication experts and more.

Daily contact occurs between DTFs and the NTF during an outbreak scenario, and indeed, members of the latter are dispatched to affected districts to support and guide their activities. DTFs themselves are composed of local disaster management and political, civic and health leaders. Other formal and potentially influential actors at the district and local level include the health workers and volunteers recruited for response from doctors, nurses, scouts, mobile and village health teams, burial teams, transporters, and more.

### Informal actors

The vast majority of literature on Ebola outbreak preparedness and response in Uganda, including this case study so far, has centred on the actions, roles and perspectives of formal response actors at various levels of the system including officials, health workers and volunteers. Much less frequently are the perspectives and actions of community members considered in these accounts, and the ways in which they experience being on the receiving end of formal governance plans and implementation, or indeed the ways in which they too 'govern' response in less visible ways. To the extent that they have been acknowledged in Uganda, the tendency is to frame them as passive recipients of knowledge through 'social mobilisation' and education efforts, which are in turn usually reported to be successful in gaining community cooperation and trust, and dispelling beliefs in witchcraft. Community actions such as swapping handshaking for elbow bumping, or neighbour-imposed quarantine upon an Ebola affected family - as happened in Masindi district during the 2000-2001 outbreak - are framed as illustrative of communities' acceptance of the reality of Ebola and formal response to the point that they take it upon themselves to initiate control measures (Okware et al., 2015). However, as explored in the next section, perspectives and responses from within

communities are more active, diverse and logical than generally portrayed by the public health and epidemiological literature which has documented Uganda's Ebola outbreaks.

## **Social science perspectives: alternative problems, alternative governance**

As discussed in the review of governance of epidemic prone infectious disease in the overarching report, social science perspectives, while making up a small fraction of literature produced in this area, bring alternative perspectives to framing and responding to disease outbreaks. This has implications for governance, including who is involved and how, as well as for objectives and goals in relation to Ebola prevention and response. Ebola outbreaks in Uganda have received anthropological attention over the last two decades, and these perspectives allow for new ways of thinking about problems and solutions in the country, and for new ways of understanding Ebola.

### **Contextualising outbreaks and response**

Firstly, social science perspectives tend to take a wider, more contextualising view of issues and events. In the context of specific outbreaks, this includes attention to factors that might be overlooked or at least downplayed by public health commenters as having an influence over outbreak emergence or containment. Some have linked the apparent success at Gulu, for instance, to strong central governance and institutions, developed over a period of political stability and growth under Museveni, which enabled a swift and coordinated response even in the conflict affected and comparatively economically and institutionally neglected north (Li & Young, 2013; McPake et al., 2015). Other more circumstantial factors have also been acknowledged. Even in the context of this degraded infrastructure, the 'urban' nature of the outbreak has been recognised as enabling the response in comparison with prior outbreaks as electricity, roads, nearby services and high literacy rates facilitated movement and communication (Hewlett & Hewlett, 2008). Furthermore, although it was the site of early nosocomial transmissions, the private donor-supported Lacor Hospital at which much of the Gulu-based clinical response unfolded represented something of an exception in the context of the weakened health system, as it was relatively well-equipped and primarily served a poor clientele of women and children (Accorsi et al., 2005; McPake et al., 2015).

The hospital's good standing among the vulnerable in the community might have contributed to the success of the response even though it was also feared as a place in which one could become infected. The extensive health education infrastructure and norms of institutional openness built up for decades around HIV/AIDS in Uganda has also been recognised as providing useful scaffolding upon which to deploy communication and public health messaging for Ebola response (Kinsman, 2012). Indeed, consistent and effective communication is frequently lauded as having been a key measure in interrupting EVD outbreaks in Uganda (Omaswa et al., 2015), although, as discussed below, this was not always as effective as public health actors have portrayed it to have been.

### **Reframing resistance**

In addition to pointing to under-acknowledged circumstantial factors, social scientists, and anthropologists in particular, have been able to contextualise and recast community 'resistance'. The Gulu outbreak of 2000-2001 was the site of what has become canonical anthropological research on Ebola for its novel documentation and analysis of community perspectives and response. Hewlett, invited by the WHO after the situation began deteriorating, was among the first anthropologists to be formally integrated into an Ebola outbreak response, with the expectation that he could help troubleshoot 'problems in the community'. People had begun to run away or hide from ambulances and refuse treatment. By talking to people with the intention to listen open-mindedly to their perspectives and concerns, they were able to deduce that it was not that people feared burial in an old airfield

designated for this purpose (as believed by response actors), but because their trust in the response had been severely damaged by the fact that families were often not informed of deaths, nor given the opportunity to view the bodies of their loved ones, or attend their burials (Hewlett & Hewlett, 2005). This, along with the opacity of Ebola Treatment Units (ETUs) – both in the sense that family members could not see what was going on inside them, and that they were often not kept informed of their loved ones' conditions – fuelled fears common to many parts of central Africa that health workers were harvesting body parts to sell to Euro-Americans (Hewlett & Amola, 2003). Community members were also concerned with the social and spiritual repercussions of failing to bury their dead in the customary way; lack of engagement with these fears and needs damaged community trust in the response, prompting people to become wary of it (Hewlett & Hewlett, 2008).

Other anthropologists have similarly documented the perspectives and actions of other communities embroiled in Ebola outbreaks in many settings (Calain & Poncin, 2015), drawing out the logics underpinning what are frequently narrowly framed by dominant voices in the public health and epidemiological community only as 'adverse reactions', 'resistance', 'reticence', or even 'recalcitrance', as in a recent WHO-AFRO piece about the recent outbreak in the DRC (WHO, 2020b). A more holistic approach allows for reframing local communities and their uncooperative or hostile responses to top-down outbreak intervention not as problems to be overcome, but as logical reactions of self-preservation and defence. Accounts which bring this more holistic perspective have been particularly abundant in the wake of the West African epidemic of 2014-2015, many of which have drawn fresh attention to these early lessons from Uganda. Indeed, in West Africa, lack of trust in otherwise neglectful national governments and foreigners was a major problem. Communities in northern Uganda too, felt neglected by the government. This fuelled rumours that the government had sent infected soldiers to Gulu intentionally, building on long-circulating narratives about a 'slow genocide' perpetrated by the state and its international allies on the Acholi people (Finnström, 2009; Hewlett & Amola, 2003).

Some public health voices have recognised how fear in communities can drive backlash. Borchert and colleagues, for instance, identified fear as the driving force behind community reactions in Masindi during the 2000-2001 outbreak. Villagers filled in graves dug by the response, mounted a violent protest at the hospital, and burned down the home of a health worker (Borchert et al., 2011). Kinsman also provided detailed descriptions of community responses in both Masindi and in Mbarara, including the storming of district headquarters, ostracising of an affected family (who happened to be of Kenyan origin) in Masindi, and threatening to attack a hospital in Mbarara (Kinsman, 2012). While it is a positive step for public health actors to pay more careful attention to these community reactions and locate them in the understandable feeling of fear rather than simply casting communities as ignorant and irrational, there is still a failure to contextualise these dynamics and local reactions in broader social and structural determinants. Thus, even when scholars may recognise important community level perspectives such as fear, mistrust or stigma, these recognitions remain largely ahistorical and power blind (Ryan, 2018).

## **Community knowledge, capacity and resources**

Anthropologists have also documented the ways in which local people and communities in Uganda have understood, explained and mounted their own 'bottom-up' responses. The Hewletts documented the 'cultural models' circulating among the Acholi in northern Uganda to explain and respond to the outbreak in locally intelligible ways. This work went beyond the usual recourse to 'witchcraft' - often the only characterisation of local beliefs in public health literature - to detail dynamic and evolving interpretations incorporating biomedical, poisoning, and spiritual explanations. Over time, they show the community coalesced around identifying Ebola as *gemo*, a cultural construction corresponding loosely to epidemic and for which cultural protocols for community-based response existed (Hewlett & Hewlett, 2008).

The Hewletts note that this protocol entailed measures which, from a public health perspective, can be considered 'broad spectrum': quarantining ill persons at huts on village edges and having survivors look after and bury them; the avoidance of sexual relations and movement within and between villages; and keeping children away from the ill, among other practices. The clear lesson emerging from this is that outbreaks do not occur in a knowledge vacuum that can only be filled by top-down communication and intervention strategies; failure to recognise and accept indigenous models for conceptualising and responding to outbreaks, even if they do not map neatly onto biomedical and public health cultural models, risks alienating people as well as failure to realise more effective responses (de Vries et al., 2016).

Another important point about community knowledge is that it should not be romanticised, and communities do in fact need support. Firstly, in addition to community practices that were helpful in combatting the outbreak, the Hewletts also documented community beliefs and practices that were indeed contributing to its spread, such as aspects of funerary practices and explanations centred around sorcery. However, it is these types of behaviours and the need to change them which formal responders and public health commentators tend to focus on, thus perpetuating an overall framing of communities and local knowledge and practice as problematic at the expense of recognising positive, outbreak combatting behaviours. Such emphasis also adds to mistrust on the part of local people if their models are flatly dismissed by responders. As de Vries and colleagues (2016) have argued, the 'big missing element' in outbreak response 'is knowing how to respectfully "agree to disagree" while simultaneously finding commonalities in humanity to facilitate collaboration during the first mile of outbreak control' (p. 11).

A second reason it is important not to romanticise community knowledge and capacities is that such communities, for the same reasons they are vulnerable to Ebola in the first place, also lack important resources that would help them use their own knowledge and abilities to greatest affect. While they may have indigenous strategies for recognising and responding to outbreaks learned over time, and do in fact adapt these as they learn (Hewlett & Amola, 2003; Richards, 2016), they must be supported.

## **Systemic and critical perspectives**

The Hewletts in northern Uganda and other anthropologists working on Ebola elsewhere have highlighted the importance of valuing local knowledge, experience and capacities so that responses might be made more culturally sensitive and effective. With greater openness, understanding and trust between communities and response actors, locals might be more empowered to take community-led action as well as engage with the formal response in ways that make sense to them, and to modify cultural and social practices that contribute to disease spread. Indeed, as Hewlett and Amola emphasise, local people are often willing to modify their practices and work with national and international responders, especially if they are treated with respect and provided with appropriate and trustworthy information and resources to do this (Hewlett & Amola, 2003). The latter point is also acknowledged by some public health commentators such as Borchert and colleagues (2011) who, in commenting on Uganda note, for example, that messages emphasising that there is no treatment for Ebola are unhelpful, and should rather focus on what communities can do to protect themselves.

While the above discussed anthropological work on Ebola in Uganda and elsewhere has not overlooked the realities of structural violence in the contexts in which outbreaks have taken place, the emphasis in this work tends to be on the unfolding of specific outbreaks and response. A critique of this narrower orientation comes from another corner of medical anthropology.

Li and Jones (2014) have argued that, while cultural and social awareness and sensitivity in disease response is important,

*[...] anthropology discards its position as a contextualizing discipline by circumscribing its role to "explaining" the enigmatic beliefs of locals for use in a behaviorist epistemology. It implicitly reinforces the assumption that behaviors are culturally determined, ignoring social, political, economic, and historical factors that affect health outcomes and disease distribution.*  
(p. 5)

They argue against an anthropology which predominantly plays the role of a 'handmaiden' to epidemiology and, in this context, is circumscribed to explaining local beliefs and supporting formal response to be more 'culturally appropriate'. A more critical view is taken, emphasising the importance of shifting blame away from local people and their culture and practices, and onto the broader power structures and systems that perpetuate poverty and disease vulnerability in Africa in the first place. While the deficiencies of the Ugandan health system and infrastructure have indeed been invoked in both the anthropological and public health literature already mentioned, attempts to contextualise this within these higher-level power structures have seldom been made (Ryan, 2018).

An exception to this, Ryan considers two Ugandan Ebola outbreaks that occurred in Bundibugyo in 2011 and Kibaale in 2012 – both in the country's western region – through this more critical lens. She links the emergence of outbreaks in these areas to the pressures of global capitalism and the legacies of neo-colonial structural adjustment policies (SAPs), which directly affected not just Uganda but the neighbouring DRC, where a lack of basic services and opportunities contributed to wars which have sent many refugees into Uganda's western reaches. Increased land pressures from this influx, as well as the fact that much of the land in Bundibugyo is designated a national park, have pushed people further into forested areas in search of food and livelihoods (Ryan, 2018).

Uganda's own raft of imposed SAPs exacerbated population pressures on an already weak health system, which, under a donor led agenda, saw little investment for basic public health and clinical care (Accorsi et al., 2005; Calain, 2007). It was upon this fragile structure that investments in surveillance have been made in Uganda. This links to another strong anthropological critique around the priority of surveillance itself, and the contemporary paradigm of 'global health security' and IHRs in which it is rooted. Focusing on and investing in infrastructure designed for rapid identification and response to infectious threats like Ebola serves to obscure the broader economic, social and political determinants of disease (Dry, 2010). Rather than serving to wage a 'war on diseases' which might be better fought by investing in basic health system functions, surveillance heavy investment better serves to wage a 'war against the circulation of specific risks', and thus mitigates against infectious threats reaching the wealthier nations which dominate global health agendas and influence and fund health system decisions in poor countries (Blouin Genest, 2015, p. 609; David & Le Dévédec, 2019). Ebola, being one such 'specific risk' which has attracted considerable attention from dominant global health actors and indeed in western popular culture, has attained 'exceptional' status. 'Ebola exceptionalism', like HIV exceptionalism, has resulted in a drive for targeted investments and programs being set up in at risk countries including Uganda, which has served to undermine attention to basic health system strengthening and other social determinants of health (Larkan et al., 2015).

The West African Ebola outbreak has brought new vigour to these arguments from the anthropological community, prompting Bardosh and colleagues (2016), for instance, to ask the question 'Whose health governance?'. Uganda itself, widely perceived as it is to have managed its own outbreaks well, has largely escaped a targeted critique of this kind (Ryan, 2018).

## Seeing power

It is not just power dynamics at the international level which social scientists concerned

about Ebola have paid attention to. Although they are certainly influenced by global dynamics – such as the underinvestment in basic care in Uganda’s health system, or the perpetuation of economic and social instabilities in the DRC – power dynamics exist at all levels including within the health system, between health system actors and communities, and within and between communities and social groups. Anthropologists have warned of the dangers of assuming that ‘communities’ are monolithic and that those considered to be ‘community leaders’ by formal response actors at the national and international level are considered legitimate by local people. This issue came to the fore particularly during the West African Ebola outbreak, with a number of anthropological papers having since been published on this topic. Anoko, for instance, described a violent backlash in the Guinean forest region where high-level response actors had tapped local chiefs to serve as leaders in the local response. These ‘leaders’, however, were not trusted by the local people, as ‘chiefs’ had only gained formal authority under colonial rule. This top-down imposition of power also butted up against the forest people’s more egalitarian social organisation. These long- standing tensions flared in the context of Ebola and resulted in the killing of a response delegation by local people (Anoko, 2014). Thus, taking these issues into consideration is crucial for response governance. While such dramatic events have not occurred in Uganda amidst outbreak response, layers of power relations do indeed condition interactions between communities and formal response actors. As suggested earlier, much of the mistrust of the state and of international actors is rooted in histories of neglect and exploitation, but complex and even potentially hostile relations are also present at local levels.

## **Communities**

The fear of Ebola (or of the other illnesses and conditions which communities may perceive it to be) can create as well as exacerbate existing inequalities within communities. In the midst and aftermath of outbreaks, survivors of the disease, family members of survivors or non-survivors, as well as response workers may face severe stigmatisation from family members, neighbours and communities, with long-lasting consequences. Anthropologists and others have documented people in Ugandan communities burning the possessions, homes and crops of people with suspected infections, of survivors and of health workers; the denial of resources, education and economic opportunities; spousal abandonment; carers being left to support sometimes many children orphaned by an outbreak, and more (see for instance Hewlett and Hewlett 2007; Ryan 2018; Kinsman 2012). In Masindi district in 2000, the emergence of Ebola in a family with Kenyan roots exposed and inflamed tensions between social groups, with the family believing that they had been poisoned by their native neighbours. Ntege (2019) found that the outbreak in the mountainous region of Bundibugyo ‘awakened dormant historical power struggles’ (p. 102) between ethnic groups in the area, the effects of which were still evident even ten years later. Failure to recognise local social dynamics and existing rifts, or the potential for them to open within communities in the event of a health crisis, risks the deepening or creation of new disempowerments (Borchert et al., 2011).

## **Community health workers**

Across Africa, community health workers are seen as a cost-effective way of connecting people who are otherwise underserved to the formal health system. In the context of Ebola in Uganda, community health workers (called village health teams or VHTs), are said to be trained in surveillance and are described as an ‘early warning system at community level’ (Aceng, 2015). During outbreaks, they have been deployed in active case searching, contact tracing, door-to-door messaging and psychosocial support. One public health paper claims that ‘since VHTs work in the very communities that elected them, they are more accepted and hence mistrust and rejection of response teams has not been reported during the recent Filovirus outbreaks in Uganda’ (Mbonye et al., 2014, p. 499). However, anthropological research in Luwero, a district which experienced two outbreaks of Ebola in 2011 and 2012

respectively, showed that community members did not necessarily feel this way. The researchers reported that many locals felt disillusioned with what they perceived to be corruption and bribery in the health system, including among VHTs who tended to be more well-off and locally powerful than most villagers, while those selected for training to be part of the DTF were certainly so (de Vries et al., 2016).

While VHTs may indeed hail from the more elite layers of local communities, they also face challenges and limitations. Musuzingo and colleagues (2017), conducting anthropological research as part of the same project in Luwero mentioned above, demonstrated that VHTs could not in fact do much about the constraints faced by community members to access health facilities. For this reason, community members perceived them as rather powerless. Meanwhile, health workers in clinics and hospitals were not very supportive of VHTs, viewing them as unknowledgeable, or even an attempt by the state to veil its failure to provide adequate health care (Musunguzi et al., 2017). Musoke and colleagues (2015) also found that VHTs seldom received supervisory support or ongoing training, and were responsible for covering large geographical areas with few colleagues. In this study, 96% of villagers interviewed either did not know if VHTs existed in their community (84%) or were sure that they did not (12%) (Musoke et al., 2015).

### **Nurses and other health workers**

Health workers at other levels of the health system have also found themselves severely disempowered. Through their work with nurses in the wake of the Gulu outbreak (as well as in the DRC), the Hewletts described the fear and pressure experienced by nurses involved in the response. Particularly salient and tough on nurses and others, and indeed already suggested throughout this report, was the issue of limited resources at hand for health workers to sufficiently protect themselves and to deliver care to patients, especially in early outbreak stages before Ebola may be recognised, or at least before formal response kicks into gear (Hewlett & Hewlett, 2005). Dealing with this, as well as with the intense stigmatisation they faced from their communities during and in the wake of outbreaks, was extremely distressing for health workers on the front lines. In the context of outbreaks, turnover was high and recruitment difficult (Borchert et al., 2011). Through ethnographic research, Ryan (2018) has documented how unsupported health workers have felt. In non-outbreak periods, concerns include basic conditions, resources and pay, and a lack of being listened to in relation to these issues, as well as for outbreak preparedness. One health worker in Kibaale, where an outbreak occurred in 2012, lamented that they had appealed for years for basic resources to handle an outbreak safely only for this to fall on deaf ears. The fact that external support, including provision of crucial resources, is only triggered after laboratory confirmation of an outbreak also leaves frontline health workers and communities highly vulnerable in the period between the start of an outbreak and its confirmation. While public health commentators have celebrated the significantly shortened time it takes for an outbreak to be confirmed via laboratory testing from the time which a sample is sent for analysis, the reality on the ground is that weeks often go by before this actually happens, and these delays may be blamed on communities for failing to recognise the disease (Ryan, 2018).

Not being heard resonates with another point made by the Hewletts. As members of the communities in which they work, local health workers may have unique insight into and even ascribe to local cultural models of disease, alongside biomedical ones. During the Gulu outbreak, however, nurses did not feel comfortable talking about these community perspectives and cultural models among their national and international colleagues for fear of coming across as ignorant (Hewlett & Hewlett, 2005). This reflects a powerful set of social norms in the medical and public health community that predominantly frames explanations and responses outside of public health and biomedical models as wrong or backward, and, if acknowledged at all, only as problems to overcome.

## Embracing a governance from below?

Given the knowledge produced by anthropologists and other social scientists, which offer alternative perspectives on what the problem of Ebola in Uganda and elsewhere is as well as elevate the perspectives and challenges of less powerful stakeholders including communities and frontline health workers, to what extent have formal governance structures responded to this and integrated these perspectives? Uganda has experienced several outbreaks of Ebola over the past 20 years, and thus has had many opportunities to shift the ways in which outbreaks are prevented, detected and handled. As earlier discussed, substantial investments have been made – with the assistance of external partners such as the WHO and CDC – in surveillance and national laboratory infrastructure, and in more technical dimensions of governance to this end. In contrast, investments or attention which illustrate reflexive movement in light of more bottom-up perspectives do not seem to have been made to a substantive degree. That said, there have been some positive moments, some of which occurred quite early on. After all, the WHO did invite the participation of Hewlett to be involved in the response at Gulu, as they believed he might be able to help assist with ‘problems’ among local people resulting in an uptick in cases. Hewlett’s participation and support led the response to be more responsive to local people’s needs in relation to transparency of ETUs and to burials in ways which were more sensitive to local social and spiritual needs (Hewlett & Hewlett, 2008). There are also some indications that families have, at least in one instance, been integrated into clinical care work and provided with training and materials to undertake barrier nursing of their loved ones in the Gulu Government Hospital during the first outbreak (Francesconi et al., 2003). A ‘psychosocial support’ domain has also been added as a formal component of response. This entails designated teams working to engage communities ‘to understand their misconceptions and misgivings’ and ‘take time to address them and discuss socially acceptable solutions which are then adopted by the response team’ (Mbonye et al., 2014, p. 498). These teams are also described to counsel patients and overburdened health workers, as well as keep families informed of their infected loved one’s status while in isolation. In public health literature, this domain is usually simply described as an element of response without much elaboration of what it looks like or how it plays out in specific outbreaks. Aside from the possibility that it may not, in fact, amount to much in the context of actual outbreaks, it is a welcome priority in governance for Ebola. A domain of response from the start, ‘social mobilisation’ is another area which would appear to have potential for the kind of listening and cooperation suggested through the social science lens. It is described to entail leaders at community level including political, religious and elders being ‘educated and sensitised’, along with traditional healers and others, as well as dissemination of media such as posters, leaflets, television and radio spots, and even live music and drama (Aceng, 2015; Lamunu et al., 2004). Although knowledge, attitudes and practices surveys are said to be deployed at the start of response to guide messaging (Mbonye et al., 2014), no evidence of this could be found. Social mobilisation tends to be primarily framed as one-way educative efforts which, along with psychosocial support, can convince populations to adopt biomedical/public health understandings of the disease, and to cooperate with the top-down response. Nevertheless, social (or ‘community’) mobilisation has been depicted by public health commentators as having been a crucial element to the containment of past outbreaks in Uganda (Okware et al., 2015).

For the most part, however, documented evidence is sparse that efforts have been made to be more meaningfully and systematically inclusive of and responsive to community and health worker perspectives over the years. There have been frustrations that early lessons from the foundational anthropological work in Uganda which illustrated the importance of listening to and incorporating the views, needs and capacities of local people into response have been forgotten, particularly in the West African outbreak (Bolten & Shepler, 2017). It has been suggested that they have been forgotten in Uganda too (de Vries et al., 2016).

Uganda is well placed to leverage this wealth of local experience and knowledge to improve its own response, as well as promote its lessons to make response more resilient elsewhere.

## Listening to communities

One of the strongest pieces of evidence pointing to this failure comes from anthropological research conducted by de Vries and colleagues (2016) in Luwero district, which has experienced two of Uganda's more recent outbreaks of Ebola (in 2011 and 2012). With respect to the 2012 outbreak, this research revealed a significant gulf between the perceptions of formal response actors (and the public health commentators who documented this) on one hand, and those of community members on the other. Framing their paper in terms of the widely perceived challenge of recognising and detecting the disease at the community level where resources and knowledge may be scarce – deemed by the authors as the 'first mile problem' – the researchers ask to what extent the community was seen and engaged with as a resource, as opposed to an obstacle to recognising and containing the outbreak. The challenge of recognition at the community level has been acknowledged by global and national health actors as requiring robust surveillance measures at the local level. In practical terms, this has meant a focus on training formal health system personnel with established case definitions practical to each level, establishing surveillance focal points and clear protocols for reporting notifiable cases upward, and enhancing technological and digital tools for quicker, upward communication. Such a strong focus on formal health system actors and biomedical understandings of the disease, however, completely precludes the role and potential of community members. And yet, in the context of an outbreak, 'social mobilisation' strategies are envisioned to catalyse the cooperation of community members with formal response, as well as their acceptance of biomedical or public health understandings.

Through careful ethnographic work, de Vries and colleagues demonstrated how 'social mobilisation' strategies at Luwero failed to accomplish this. This failure is attributed to several factors. The emergence of illness within one family, and a diagnosis by a traditional healer, confirmed to the community they were witnessing a case of *amayembe*, or evil spirits. This conviction interacted with 'historical mistrust of a chronically underfunded medical system' (p. 7) which was reinforced throughout the response, including through the explicit dismissal of the *amayembe* explanation, framed by outreach teams as a misconception that needed to be dispelled by 'the facts'. Secondly, the supposed financial disbursement of nearly US\$200k for response did not appear to materialise in any way which helped local people, further entrenching a suspicion of corruption in the health system and a feeling that, as poor people, the government did not really care about them. Response arrived late. Patients were not supplied with adequate food, and a survivor later discovered he should have received a package of food and clothing to compensate for the destruction of his possessions. A lack of sensitivity and respect caused further alienation. Patients' belongings were burned in front of them. Burials were perceived to have been handled carelessly, and relatives wanting to be involved in caring for, or at least kept informed about, their family members were ignored. Community member's 'resistance' to the biomedical model was eventually met coercively. Armed personnel presided over a 'sensitisation meeting' which one informant claimed was attended under 'the barrel of a gun' (de Vries et al., 2016, p. 7).

Clearly, local people were unswayed by social mobilisation efforts even while an evaluation suggested that it was ultimately successful, if challenging (de Vries et al., 2016). That this outbreak did not spread beyond one family is likely more a result of the technical dimensions of response, the competence of health workers even in the absence of support initially, and the coercive strategies eventually deployed by response actors. At the same time, the fact that local people's belief models were not taken seriously and indeed explicitly dismissed, alongside the poor treatment of patients and the community generally, is likely to have more

deeply entrenched feelings of mistrust in the formal health system and the state in this already marginalised community. As de Vries and colleagues put it,

*...what characterizes this case study is the shared experience of community members that the DTF and its partners lacked openness and willingness to take the time needed to listen to and empathize with community needs. After all, what these community members were seeking first and foremost were strategies to take care of their fellow human beings and to diagnose and explain within their own cultural framework. (p. 10)*

## **Strengthening health systems**

As is clear from the account of de Vries and colleagues, health system weaknesses compromise local people's trust in the Ugandan state. While their example emphasises the mostly overlooked perspective of local communities, frontline health workers and other responders also exist and must operate within a system which disempowers them. Indeed, as presented earlier in this report, the limitations and shortcomings of the health system, particularly at its lowest levels, have been acknowledged by public health actors commenting on Ebola in Uganda. But to what extent has governance for Ebola in the country actually taken seriously the importance of basic health system strengthening and equity to outbreak prevention and response, as emphasised by social science perspectives?

Some of the challenges facing frontline health workers in the context of outbreaks have been met with modest, arguably ad hoc improvements. During the Gulu outbreak, for instance, demands from exhausted and terrified health workers for risk allowance, as well as for compensation to the families of health workers who died from Ebola, were eventually met (Kinsman, 2012). This compensation was reported to have been severely delayed following Gulu, however, and the additional risk allowance was framed by health workers as inadequate in later outbreaks (Ryan, 2018; Wendo, 2001). In the wake of outbreaks, some infrastructural improvements are also reported to have been made, such as the development of a new purpose-built isolation ward at Lacor Hospital in Gulu (Lamunu et al., 2004).

A more holistic picture of the extent to which 'health system strengthening' has occurred comes from Ryan (2018). Focusing on Bundibugyo and Kibaale districts, which suffered outbreaks in 2007 and 2011 respectively, she notes both the poor conditions and capacities of local health facilities and staff prior to the outbreaks (and thus illustrates how minimal investment has been in basic health system functions), as well as the extent to which enhancements were made following them. Indeed, she demonstrates that rather than any attempts to improve the resilience and capacity of the health system in these districts, an 'active process of reverting things back to "normal"' – how they were before the outbreaks – occurred (Ryan, 2018, p. 224). With a perspective of two and seven years out from each respective outbreak at the time of her data collection, and four years beyond that at the time of writing, Ryan notes that despite there having been some talk of investment, no action had been taken. Facilities and health workers in these districts had been left to manage as usual with few resources, and under intensified pressure due to the many refugees fleeing conflict in the DRC. Ryan interprets this process as an example of 'Ebola exceptionalism', in which systems and resources are deployed from the centre and international community to address an outbreak of Ebola in which these high-level actors have an interest in stopping, only for this support to be retracted following successful containment and thus leaving disempowered health actors and populations to contend with high burdens of endemic diseases which are of less interest to powerful actors, and yet which exact significant tolls on poor communities.

As suggested elsewhere, there exists a power imbalance not only on a global scale in terms of agendas and priorities, but also within health systems. In Uganda, resources and capacity for Ebola response are highly centralised and lower level actors are highly vulnerable. An example

of the disempowering relationship between district level health staff and central authorities in the context of an outbreak comes from the manager of a health centre in Luwero. Not only does he describe the poor baseline conditions of his and other similar facilities, such as minimal space, no running water, a skeleton staff and very few supplies, but he details his attempts to reach out to the MOH when he and his team suspected they had an outbreak on their hands (Nkonwa, 2015). He describes his superiors' treatment of him as dismissive, perceiving this to be at least partially due to his youth, low station, and small facility. The district team was asked to manage until a response team could be sent.

After four days without support other than provision with extra gloves, they sent their own sample in a vaccine box with a health worker in a taxi to Kampala. Confirmation took ten days, and it was only after this confirmation that representatives from the MOH arrived with support. Ryan (2018) has also highlighted that in both Kibaale and Bundibugyo, it was not the fact 'that people were becoming ill and dying from an unknown infectious disease' (p. 192) that triggered external support, but official laboratory confirmation. These delays result not only in lives lost, but communicate to local people and health workers that their lives matter only if threatened by Ebola, as well as undermine trust in other ways. De Vries and colleagues (2016) note, for instance, that community members in Luwero interpreted the delay in government support as evidence that what they were experiencing was not really Ebola, and that if it was, support would have arrived sooner. On top of this, local actors are also often blamed for transmission and delays. In relation to communities, this takes the form of 'cultural epidemiology' in which people's practices and beliefs around burial or visits to traditional healers, for instance, may be blamed for spread and delay, while health workers may be cast as having failed to make key decisions or take important precautions – even as they are actually all rather disempowered (Ryan, 2018).

## Supporting survivors and others

In focusing on the experiences of local people, social science approaches also direct attention to the experience of being a survivor of Ebola, or being associated with an outbreak in some other way such as a carer of orphaned children or a health worker, after an outbreak is over. Although stigma is acknowledged as an issue for survivors and others following outbreaks, public health literature tends to make only brief mention of this, and ends its stories with the containment of outbreaks. Even in social science literature, however, this is an area which has not seen as much attention as community experiences and perceptions during outbreaks. As earlier suggested, some recognition of the challenges of survivors, survivors' families and health workers, and attempts to support them, have been made in Uganda. This includes, for instance, the already discussed additional risk pay for health workers and compensation packages for their families in the event of their deaths.

The MOH's Standard Operating Procedures (SOPs) for responding to Ebola published in 2015 indicate that survivors, prior to being discharged from an ETU, should be informed to expect stigma, counselled on some 'stress management skills', and provided with compensation for any lost property (Uganda MOH, 2015). One example from Luwero, in which a survivor later learned he had been entitled to receive compensation and yet did not, reinforced perceptions in the community of corruption (de Vries et al., 2016). The SOPs also indicate that post-outbreak assessments should be conducted by district personnel to identify serious cases of posttraumatic stress, and to help survivors regain livelihoods, while arrangements for orphans should be made with surviving family or local NGOs. Although it is unclear which outbreak he is referring to, Okware (2015) indicates that 'post Ebola clubs' were set up for survivors to provide 'humanitarian needs' including food rations, while Kinsman (2012) also suggests that, to fight stigma, communities in Gulu were 'educated' following outbreaks to ensure they understood that survivors were no threat to them. Although anthropological perspectives on the experiences of survivors and others following an outbreak in Uganda are few, there are some accounts which emphasise the ongoing challenges for these local people. One woman

profiled by Ntege (2019) was still unable to find steady work or a husband even ten years after the outbreak at Bundibugyo. She lamented that community members, believing her to be cursed, would not visit her at home where she lived alone. She described herself, particularly in the months following the outbreak, as 'socially and culturally dead', and found the repeated visits from medical researchers, who turned up to take her blood on a regular basis and yet did nothing to help her, upsetting (Ntege et al., 2019). There were no accounts of sustained support to survivors, and yet it is clear that where outbreaks have emerged they have had enormous and long-lasting impacts on already vulnerable people's lives. The little attention to this in the literature suggests this is a neglected part of epidemic governance.

## **An alternative for Uganda: Meeting the governance challenges of scale, intersectorality, inclusivity, and interdisciplinarity**

Considering often overlooked insights from the social sciences in relation to outbreaks – many of which come from within Uganda itself – how can governance for Ebola in the country be made to be more effective in terms of preventing and responding to outbreaks, as well as speak to people's multiple needs? Social science contributions, despite the little attention they receive in the context of outbreaks, help us to re-frame what is considered to be the problem, and thus what appropriate solutions might be. Below, we highlight four key challenges which spring from these re-framings that we believe need to be addressed to make governance for preventing, identifying and stopping outbreaks of Ebola in Uganda more effective. Addressing these issues will not only help fill some of the more obvious gaps in governance, but, if pursued in a power-aware and reflexive manner that centres equity and the needs of local people and health workers, will help build trust between communities, the health system, the state and global institutions.

### **Scale**

There is a need to ensure governance for Ebola reaches across temporal, institutional and spatial scales. Firstly, the kinds of systemic factors highlighted by critical anthropologists of outbreak emergence and response point to the need to widen the temporal frame used to think about and address outbreaks. This thinking must move beyond a focus on pre-outbreak 'preparedness' and the technical measures associated with this that have been pursued in Uganda, such as the upgrading of laboratory capacities, strengthening surveillance systems through health worker training and institution of technological communications systems, and establishing and sustaining taskforces that can mount rapid response as necessary. As suggested above, it must also encompass more attention to addressing the systemic roots of disease emergence and spread in poverty and vulnerability. These are much longer wave dynamics than surveillance systems are tuned to pay attention to and they require more systemic and structural reforms, some of which may take much longer to realise and are indeed less tangibly attributable to specific actions, strategies or plans for Ebola or any other specific health issue. It is equally important for governance to expand the relevant temporal frame forward, beyond the period of an outbreak to more substantively engage with the ongoing social, psychological and economic challenges faced by survivors, family members and health workers in the aftermath of outbreaks. As illustrated in Uganda, these negative effects may be felt years into the future. Better governance for Ebola must also more meaningfully engage across institutional and spatial scales, from the global to the most local of levels. Indeed, it is the people and institutions at the local level – both formal and informal – that have been most neglected in Uganda. Power is disproportionately concentrated at the national and global level and more must be done to empower local people to make decisions and act locally, as well as to have their perspectives and interests centred in national and global governance.

## Inclusivity

Social science perspectives have demonstrated how failing to include the perspectives and priorities of local people and frontline health workers in outbreak governance can result in understandable rejection of top-down response. This recognition shifts the problem framing from one which positions communities, their culture, beliefs, practices and 'resistance' as obstacles which must be overcome with top-down educative and even coercive strategies, to be one which rather emphasises that a lack of respect and openness on the part of formal responders towards community perspectives can lead to understandable hostility, and thus potentially ineffective response in the short term, and wreak further damage to trust in formal institutions and the health system in the longer. However, bringing meaningful attention to the challenges, priorities and knowledge that exists at the local level requires more than just bringing local issues to the attention of elites. Certainly, it means active listening by the latter to the former, and creating space for and empowering local people to sit at the table of governance at all levels, as well as to 'govern from below'. This does not mean communities should be left to deal with situations on their own, but rather emphasises that their valuable knowledge about how an outbreak may be moving through a community, as well as how it can be addressed in ways aligned with local cultural frameworks and with sensitivity to local social, spiritual, and economic needs, can and should guide response through processes of mutual learning and cooperation. Including local people's perspectives, especially those of the most marginalised, can also bring attention to the longer-wave dynamics mentioned above: the stresses and pressures that render people and communities vulnerable not only to Ebola, but to legions of other endemic infectious diseases and other ills of poverty. It is also crucial, however, not to assume that communities are homogenous, and efforts must be made to reach out to and elevate diverse perspectives, especially those of the most marginalised. Health workers and community health workers, while they may have insight into local explanatory models, may not necessarily be the most trusted individuals in a community, and thus being aware of local power dynamics is important. That said, local health workers are crucial to response, and they too must have a seat at the table of governance. Relying on ad hoc training of these important local actors does not do much if resources and sustainable support are not available to them. With more of a say, these actors can advocate for themselves and help guide preparedness efforts, response, and general health system strengthening. Another set of ignored local actors who should be more meaningfully engaged are traditional healers. While they were banned amidst the Gulu outbreak for fear they might have been spreading the disease through their practices, it is unclear to what extent, if any, they have been included in later outbreaks. One article from 2019 suggests that at least one healer in western Uganda had been trained as a 'community influencer'. He did not treat Ebola, displayed an informational sign at his home, knew the hotline number by heart, and is described as having 'lashed out at some community members who peddled rumours that Ebola is some form of witchcraft' (Taremwa, 2019). Thus, at least in this case, a healer has been engaged in surveillance and top-down 'social mobilisation' strategies dismissive of local explanatory models.

## Intersectorality

The factors and drivers which give rise to Ebola outbreaks in Uganda and elsewhere are complex and manifold, and shaped by policies and issues in areas far beyond those which directly address health. Thus, building resilience to outbreaks in Uganda requires a 'health in all policies' approach. For instance, pressures that drive marginalised people into forested areas for economic activities where they are more vulnerable to Ebola are not necessarily inevitable. More robust policy orientations to support people, including Congolese refugees, to access food and livelihood activities which do not require them to risk infection can help with this, for instance. 'Health security' on an individual level is inextricably bound up with other forms of security including economic security, food security and social security. This

view thus requires an acknowledgement that formal 'governance' for Ebola happens not only in spaces where Ebola is the policy target, and indeed involves decision makers in different areas who should be sensitised to consider the health implications of their decisions, including by ensuring that citizens themselves have a place at the table. In addition to the broader policy environment which shapes the opportunities and vulnerabilities of local people, the challenge of intersectorality is applicable directly to governance for outbreak preparedness, response, and, indeed, the post-response period. Uganda's National Taskforce and District Taskforces are made up of leaders from across different sectors and designate subcommittees for handling different domains of response including coordination, surveillance, laboratory, case management, psychosocial support, social mobilisation and security and logistics (Uganda MOH, 2015). While this represents a good array of different areas that require attention during an outbreak, some of Uganda's later outbreaks have not necessarily delivered in all areas, particularly in post-outbreak support. Health workers, survivors, and the families of Ebola victims continue to experience stigma and discrimination long after outbreaks, and may face new burdens such as having to absorb orphaned children with little to no support. Social protection for these individuals is a key element to just outbreak governance, and for ensuring individual health security and community resilience to future stresses and shocks. This might be strengthened through improved social safety nets and protections following outbreaks and the empowerment of civil society, resources for which might come from donors and external actors who are otherwise very keen to invest in other aspects such as surveillance infrastructure for early warning and other technical 'preparedness' activities.

## **Interdisciplinarity**

Ugandan authorities have taken the threat of Ebola seriously, and should be lauded for this. However, investments in this regard have tended to reflect a particular disciplinary orientation towards epidemiology, the biomedical sciences, and public health. This of course reflects the slate of contemporary global health priorities which centre 'preparedness' primarily in the form of surveillance for early warning, and for rapid technical response for containment. Reliant to a large extent on donors and external resources, Ugandan health priorities similarly reflect these imperatives. Opening up governance at the global, national and even sub-national level to social science perspectives can make decision making and resource allocation more equitable and responsive to Ugandan people's needs and capacities before, during and beyond outbreaks, through attention to the three above-described challenges. Sensitivity and action on the broader determinants of outbreak emergence at multiple scales - such as, for instance, poverty and vulnerability sustained by particular economic orientations and at the global level, but also nationally and locally through the reach, functioning and quality of the basic health system - can help build resilience against the likelihood of outbreaks occurring in the first place. Greater attention and openness to cultural models and knowledge of disease, and supporting the capacities of local people to engage with or even lead response in ways which make sense to them and speak to their needs can ensure more effective responses, as well as lay foundations for trust between communities and the state and health system. Attention to contextual specificities, including the complexities and layers of power dynamics in which state actors, communities and people are embedded, can help guide any action for Ebola, and indeed for health in Uganda more broadly. The same dynamics which alienate and pressure workers at subordinate levels of the health system and which strain community trust in the health system, state and international responders, threaten not only Ebola-specific interventions, but action for health and wellbeing more broadly. With their focus on these normally overlooked aspects, as well as skills for drawing out and bringing together diverse perspectives, including those least often heard, social scientists can bring much to the table of governance. To date, however, institutional pathways for integrating social science perspectives and participation more firmly into governance remain nascent, particularly with regard to more critical perspectives, and anthropologists have often had to assert themselves,

even 20 years after Gulu.

## Conclusion

Uganda has been praised for its efforts and political will to invest in outbreak preparedness and response, and has been recognised as a positive example among low-income countries for its progress in implementing the 'global health security agenda'. Indeed, it has long had operational plans in place in the event of an outbreak of Ebola or other serious infectious disease, which trigger the constitution of taskforces at the national and district level and the mobilisation of technical support and resources for containment. With the support of external partners, particularly the WHO and CDC, Uganda has also made remarkable technological innovations and enhanced its physical infrastructure and capacities, including the establishment of an in-country laboratory capable of testing for Ebola and other filoviruses, an Emergency Operations Centre from which outbreaks can be coordinated, and improved infrastructure at some hospitals with, for instance, specialist isolation wards. It was also an early adopter of WHO surveillance strategies (IDSR) and has in place protocols for upward reporting from the community to national level through focal points and with the support of technological and digital tools. Training of local level personnel to implement surveillance and response protocols is also undertaken and ramps up when outbreaks occur in other countries, such as during the West African outbreak and, recently, during the outbreak in the neighbouring DRC. These achievements, while remarkable, have generally insulated Uganda from more critical scrutiny, especially among the global health community which has instead, especially in recent years, tended to reserve critique and reflexive commentary for the drivers, circumstances and governance of the West African epidemic.

While it has made remarkable strides, focusing on these technical advances and protocols in Uganda obscures the very real challenges which still exist, particularly at the local level. While public health actors commenting on individual outbreaks do recognise the limited resources available at the local level and the general weakness of the public health system, what is emphasised as the problem tends to be the delay in recognition of the virus at the community level. This has usually been met with renewed calls for training rural health personnel in surveillance. Despite Uganda having been the site of pioneering anthropological research which documented a local community's ability to both recognise and respond to an outbreak using their own local expertise (even if this did not map onto biomedical/public health models), the true potential of local people to address this problem of the 'first mile' has not been adequately supported in the country. And yet, given the limited reach of the formal health system, and the mistrust that many people in marginalised communities have of it and of the state and outsiders generally, training rural personnel and local leaders for surveillance and top-down response focused on getting people to abandon their 'wrong' beliefs and to cooperate seems to remain the dominant strategy to address this gap.

Thankfully, Uganda has not had any major Ebola outbreaks in recent years, and the limited scale of its most recent ones may indeed be attributable to the formal protocols and institutions in place, as well as to the actions of local people – even if the informal contributions of the latter, beyond their cooperation with formal responders, are seldom recognised. More meaningful engagement, listening and openness to community perspectives and needs may help prevent deaths and tragedy in the short term whilst building community trust in formal institutions. This will enhance resilience to outbreaks as well as to other shocks and stresses in the long-term. Furthermore, without attention to the broader drivers of vulnerability to Ebola, which indeed also drive vulnerability to many other infectious diseases in Uganda and across sub-Saharan Africa, governance fails in both reducing the likelihood of future outbreaks, and in protecting individual health security if its focus remains on rapid detection and response to specific threats of interest to wealthier populations in the global north. Central authorities in Uganda, but also at the global and international level, with the power to mobilise resources and define agendas should devote

adequate attention to strengthening basic health system functions and combatting poverty and vulnerability in Uganda. Doing this will require greater attention to meeting the challenges of scale, inclusivity, intersectorality and interdisciplinarity. Furthermore, already the site of foundational anthropological research demonstrating the importance of centring the challenges, knowledge, capacities, needs and priorities of local communities in the context of Ebola, Uganda can become a leader in defining new 'people-led' governance for Ebola. As Bardosh and colleagues (2016) have argued,

*The foundation for epidemic control should be located in inclusive institutions and economies that generate trust, justice, equality and security in social milieus. Building inclusive institutions demands "people-led" politics: taking seriously the challenges and claims of communities, activism and grassroots ingenuity to dominant modes of power. (p. 91)*

## List of acronyms

AFENET	African Field Epidemiology Network
CDC	US Center for Disease Control
DFID	UK Department for International Development
DRC	Democratic Republic of Congo
DTF	District Taskforces
EOC	Emergency Operations Centre
EVD	Ebola Virus Disease
GNI	Gross National Income
GOARN	Global Outbreak Alert and Response Network
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
IDSR	Integrated Disease Surveillance and Response
IHR	World Health Organization's International Health Regulations
IMT	Inter-ministerial Taskforce
JEE	Joint External Evaluations
LMIC	Low-to-middle-income Country
MOH	Ministry of Health
MPRP	Uganda National Multi-hazard Preparedness and Response Plan for Public Health Threats and Emergencies
MSF	Médecins Sans Frontières
NTF	National Taskforce
PHEIC	Public health emergency of international concern
PPE	Personal protective equipment
RRT	Rapid Response Team
SMS	Short Message Service
TB	Tuberculosis
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UVRI	Uganda Virus Research Institute
WHO AFRO	World Health Organization Regional Office for Africa
WHO	World Health Organization

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