# Ebola in the DRC: The Perverse Effects of a Parallel Health System









The Congo Research Group (CRG) is an independent, non-profit research project dedicated to understanding the violence that affects millions of Congolese. We carry out rigorous research on different aspects of the conflict in the Democratic Republic of the Congo. All of our research is informed by deep historical and social knowledge of the problem at hand. We are based at the Center on International Cooperation at New York University.

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Cover photo: 17 January 2019, Beni, North Kivu region, Democratic Republic of Congo. A doctor talks with Julie, in her cube at the Ebola Treatment Center. *Photo: World Bank / Vincent Tremeau* 



# **Table of Contents**

Executive Summary	4
Introduction	5
Ebola: From Neglected Tropical Disease to Global Health Security Threat	7
Medicine in DRC: From Colonial Tool to Site of Extraction	8
The Building of a Parallel Health System	11
Mangina: May-July 31, 2018	12
August 1, 2018-May 2020	14
Box: The "Foreignness" of the Response	16
The Response and the Community	19
Sensitization	20
Contact Tracing	24
Safe and Dignified Burials	25
Vaccination	26
The Response and the Existing Health System	29
Triage	29
Active Surveillance	30
Transit Centers	31
Ebola Treatment Centers	31
Conclusion	33
Methodology and Baseline Data	35
Fndnotes	36



# **Executive Summary**

On August 1, 2018, the tenth epidemic of Ebola in the DRC was declared. While the country's nine previous epidemics were relatively small in scale, managing Congo's tenth Ebola epidemic, the world's second largest to date, was especially challenging. The normal difficulties of containing an infectious disease in urban areas with limited running water, a mobile population, and a weak healthcare system were exacerbated by conflict dynamics that have affected the region since 2013. Despite significant international investment, the epidemic took nearly two years to contain and cost over 2,200 Congolese lives.

This report, the first of three to be published by the Congo Research Group on the epidemic, examines the public health aspects of this international response. We argue that this epidemic emerged at the intersection of two histories—the perception of Ebola as a global health security threat and the privatization and decline of the Congolese health system. Both trends led the donor community to create structures parallel to the existing health system and led largely by outsiders. Viewed with suspicion—many thought these outsiders had come to profit from the disease—this parallel system struggled to be accepted, leading to a lack of collaboration with local communities and even violent attacks, feeding into a cycle of militarization.

Immense scientific and clinical advances during this epidemic have revolutionized the care of Ebola and transformed Ebola into a vaccine-preventable and treatable disease. Yet the fact that the response remained external to the health structures familiar to the community significantly compromised its efficacy, potentially prolonging the epidemic and contributing to violence.

This approach is not unique. In recent decades, donors have responded to the dilapidation of the Congolese health system by designing interventions that target specific diseases, often through parallel structures. While these are short-term fixes, they end up compromising the existing health system in the long term and fail to effectively contain disease. If future epidemics are to be prevented or contained effectively, the Congolese health system must be rebuilt, which would allow international epidemic responses to be reduced to a support role or eliminated altogether.



# Introduction

For forty years, Ebola remained a neglected tropical disease affecting relatively few and limited to central Africa. The virus then took on a greater international profile in West Africa in 2014, where it killed over 11,000 people. The epidemic there overwhelmed health systems in Guinea, Liberia, and Sierra Leone. With minimal access to appropriate personal protective equipment, triage, and measures to control the spread of infection, health centers transformed from spaces of healing to sites of amplification of the disease—other patients and healthcare workers contracted Ebola within the health centers themselves. Healthcare professionals became sick and died, while health centers and hospitals shut their doors. Closed hospitals meant high fatality rates for those with Ebola, and significantly worse health outcomes for those sick and dying with non-Ebola conditions. For the first time in history, Ebola had affected the health systems of an entire region. In August 2014, the World Health Organization labeled Ebola a Public Health Emergency of International Concern (PHE-IC). Despite significant international investment, the damage wrought in these countries was extensive. In addition to the death toll of Ebola, it was estimated that as many people died of preventable deaths due to malaria, tuberculosis, and HIV/AIDS because of reduced healthcare during the epidemic. Moreover, this estimate does not account for the loss of life due to the reduction in healthcare services caused by the dearth of healthcare workers and healthcare funding.

When, on August 1, 2018, a new Ebola epidemic was declared in DRC, memories of the West African epidemic resurfaced. At the same time, there were differences: great advances in the prevention and care of Ebola had been made during and since the West African epidemic. A vaccine had been developed, and some novel treatment molecules had been tested. Yet, in the Congolese context, where health systems were already weakened by decades of structural adjustment, state collapse, and war, experts evoked the specter of "another West Africa."

There had been nine previous Ebola epidemics in Congo, most of which had been controlled in a matter of months. But because this particular epidemic emerged near an urban area and on trade routes that extended to East Africa, the Middle East, and China, experts feared regional spread and health system collapse. <sup>10</sup> In the end, massive international resources were mobilized to form the Response. <sup>11</sup> This coalition of Congolese government officials, UN agencies, and humanitarian organizations were eventually able to effectively control the epidemic. Unlike the tragic collapse of national health systems as in West Africa, something else occurred in Congo: the creation of a massive, parallel, disease-specific healthcare system that was detached from both the community and existing health structures. This system—and its impact on the local population—are the subject of this report.

While much operational research was conducted during the epidemic by those working within it,<sup>12</sup> violence in the region limited broader analyses about what the fight to stop the tenth Ebola epidemic in eastern Congo actually looked like.<sup>13</sup> From a public health perspective, incredible clinical advances were made during this epidemic that had the potential to limit its duration and toll. Yet over 2200 lives were lost in the world's sec-



ond largest and longest epidemic to date. What mistakes were made? And what must change so that a similar scenario is not repeated during the next epidemic, whether Ebola or another emerging infectious disease? The answers to these questions extend beyond the responsibilities of particular individuals or organizations. To understand how this particular epidemic unfolded, we must take into account the broader context of public health in the Congo, as well as the relationship between this Response and existing structures of violence in a region that has long been marked by conflict.

In this report, we focus on structural violence, which is often overshadowed by more visible scenes of killing and mutilation in the media. Structural violence, which can manifest itself through broad processes such as colonialism, racism, capitalism and patriarchy,<sup>14</sup> is difficult to analyze because it often acts through systems instead of individuals, creating hierarchies in which certain lives are valued over others: people in the Global North over the Global South, white lives over Black lives, or men over women.<sup>15</sup> This structural violence then generates physical violence, and both forms reproduce themselves over time.<sup>16</sup> In this report we will describe how this kind of silent violence has dramatically impacted healthcare and epidemic management in eastern Congo.

This report begins with histories of the Ebola virus and the Congolese healthcare system to provide the context in which the tenth epidemic broke out. Then we describe the Response—its creation, how it evolved over time, and its relationship to the population and the existing health system. We show how the Response emerged at the intersection of the global health security apparatus and a regime of devastating structural violence in Congo. Next, we explore the parallel health at the center of the Response to this epidemic: its structure, its function, and its effects. Overall, we argue that the Response helped generate new forms of violence that severely undermined containment efforts, concluding with a proposal for how epidemic management in Congo and elsewhere could be done otherwise.



# Ebola: From Neglected Tropical Disease to Global Health Security Threat

First identified in DRC in 1976 by Professor Jean-Jacques Muyembe,<sup>17</sup> Ebola was long understood to be a disease that affected only those who lived within Africa's equatorial forests. Prior to 2014, some 21 Ebola outbreaks had been recorded in central Africa (Sudan, DRC/Zaire, Gabon, Uganda, Republic of Congo), most affecting fewer than 100 people, all with fatality rates less than 500.<sup>18</sup> For many years, Ebola remained a neglected tropical disease.

In the early 1990s, following the end of the Cold War, the U.S. and other countries became increasingly concerned with the threat of terrorist groups,<sup>19</sup> including the possibility that they could engage in biological warfare. This sparked a renewed national interest in mitigating the risk of possible biological weapons.<sup>20</sup> In the name of national security, national laboratories were tasked with the development of vaccines and treatments to infectious diseases like Ebola, that could be used in biological warfare. In 1995, the quest for an Ebola vaccine began.<sup>21</sup> This fear of Ebola was not limited to governments. Rather, as "outbreak narratives" dramatizing Ebola emerged in the 90s, Ebola entered the popular imagination as a grotesque, apocalyptic killer.<sup>22</sup> The fact that until then, Ebola had only killed Black people made it more exotic—and more feared.

The SARS epidemic in 2002 demonstrated how infectious diseases, whether spread intentionally or not, had the potential to profoundly damage even well-structured health and economic systems. As a result, significant resources began to be allocated to disease tracking and vaccine and antiviral stockpiling worldwide.<sup>23</sup> To coordinate the efforts of individual countries into a global effort, the WHO developed the International Health Regulations (IHR), which bound its signatories to invest in systems that could detect and intervene in emerging infectious diseases. As attention in the U.S. and elsewhere moved from protecting against biological warfare to preparing for pandemics, infectious diseases began to be understood not just as threats to human lives, but to global security more broadly.<sup>24</sup> New global public health systems were built to detect and fight emerging infectious disease in the name of global security. Given its high fatality rate, Ebola was one of the viruses used in the modeling and design of these new systems.<sup>25</sup>

In 2014, the model became a reality when an Ebola epidemic broke out in West Africa. No longer was Ebola a neglected tropical disease, or even an emerging infectious disease. The UN Security Council now described Ebola as "a threat to international peace and security." <sup>26</sup>

Given its new designation as a global security threat, Ebola now demanded resources and tactics of a different scale. Facing spiraling infection rates and a collapsing health system, *Médecins Sans Frontières* (MSF), long committed to political autonomy and non-militarized intervention, called for the international community to deploy their respective armed forces to help with large-scale logistical aid.<sup>27</sup> Governments responded to the call and soon there were foreign troops on the ground in West Africa. Given that Guinea, Sierra Leone, and Libera had very recent memories of war, the militarization of the international response engendered significant fear on the part of many.<sup>28</sup> Eventually, the epidemic was brought under control. However, the precedent of



deploying foreign armies to manage a public health emergency was set, solidifying the link between military forces and the control of infectious disease that began in the 1990s.<sup>29</sup>

As had happened in prior responses, the militarization of the response in West Africa worsened pre-existing social and economic divides. In the name of the protection of some, foreign militaries contained and isolated others, often brutally so. These two groups—those who deserved protection and those who necessitated containment—were often split along social hierarchies of skin color, class, and geography. The militarization of the West African epidemic created the possibility for violence against those determined to be "public health offenders"—often poor, Black people—so as to prevent spread of the disease to the Global North.

The declaration of Ebola as a threat to global security also created new possibilities for research. Because Ebola previously had only affected poor regions of the world, Ebola research did not garner the attention of for-profit ventures and was instead relegated to national laboratories. The heightened threat of Ebola opened up a new market for research. Pharmaceutical and biotechnology companies developed rapid diagnostic testing,<sup>31</sup> and trialed several vaccines and treatments.<sup>32</sup>

In addition to these marketable products, new treatment protocols were developed with the arrival of Ebola in research-rich hospitals for the first time. Where all available resources could be dedicated to the treatment of a handful of patients with Ebola, case fatality rate was driven down from 62 percent in the West African setting<sup>33</sup> to 18.5 percent in Europe and the U.S.<sup>34</sup>

# Medicine in DRC: From Colonial Tool to Site of Extraction

Ebola epidemics do not occur in a vacuum. Rather, they emerge in a context shaped by a specific historical and institutional landscape. In West Africa, the virus emerged in a region whose healthcare systems had been weakened by a decade of war. As hospitals quickly transformed from treatment centers to transmission hotspots, the epidemic blossomed.<sup>35</sup> A brief detour into the history of public health in the Congo is therefore important.

As was the case in many colonies, in Congo, biomedicine—the understanding of illness as rooted in biological pathogens and the use of vaccines and pharmaceuticals to prevent and treat illness—was introduced as an arm of the colonial state, used to control the population and ensure a healthy workforce.<sup>36</sup> This approach contrasts to more traditional understandings of medicine in Congo, which often rely on the spiritual or occult world for explanations of illness, and the botanical world for healing.

Under the Belgian colonial system, biomedical healthcare was not a right or a public good; instead, it was provided and mandated to keep workers on rubber plantations in working condition, to increase Congolese women's fertility and child-bearing for the prosperity of these plantations, and to minimize the effects of infectious disease (including syphilis) on the Belgian colonists running plantations.<sup>37</sup> Coercive and often brutal



means were used to ensure that Congolese subjects left traditional healers and began frequenting Belgian-run clinics and hospitals.<sup>38</sup> While few Congolese have specific memories of the coercive and violent biomedical regime during this period, this violence of the colonial state shaped the general preference for traditional understandings of illness, which continues today. Many in Congo continue to report feeling more comfortable with medicine that their ancestors used than they are with the "white man's medicine [dawa ya muzungu]."<sup>39</sup>

In June 1960, the DRC achieved independence from Belgium. However, because biomedicine had been the domain of colonial missionaries and state agents, there were few trained Congolese healthcare workers. Instead, Belgian healthcare workers continued to provide most healthcare during early independence.<sup>40</sup>

In the 1970s, Mobutu's regime began working to develop a nationalized, decentralized healthcare system free from Belgian influence. Like the colonial system that preceded it, this was also a biomedical system. However, where the colonial system had pitted biomedicine against traditional medicine, these healthcare initiatives put an emphasis on public and community health, thereby sidestepping the earlier divide. Much like traditional medicine, Mobutu's healthcare system took seriously the idea that nationalized primary care would improve the health of the nation. As such, it included clean water, sanitation, treatment of most common ailments, maternal and infant health, family planning, and the provision of essential medicines. While nurses and physicians were included in the model, unpaid community health workers called *relais communautaires* formed its base.

For a short time, the system functioned well—public health experts even identified it as one of sub-Saharan Africa's model health systems.<sup>44</sup> Still, the state collapse that began in the early 1980s spared nothing. In the wake of disastrous management and theft of state finances, coupled with the austerity of structural adjustment policies, Mobutu was forced to cut public health expenses and then introduced user fees to help keep the doors open.<sup>45</sup> Within a decade, the majority of health centers had been privatized, and the robust national healthcare system had been transformed into a weak and often predatory market-based system.<sup>46</sup>

Non-state actors—initially the church and then later, NGOs—have always contributed significantly to healthcare provision throughout Congolese history. Even during the height of nationalized healthcare in DRC, primary care in two-thirds of all health zones was supported by the church via the Santé Rurale (SANRU) program.<sup>47</sup> With the beginning of the first Congo War in 1996, international NGOs entered the country en masse. The state's role in healthcare became limited to "a legal framework for non-state actors."<sup>48</sup> Disease-specific financing was introduced. Instead of supporting the larger healthcare system, donors supported specific populations defined as vulnerable (such as those suffering from HIV/AIDS, tuberculosis, malaria, and sexual violence).<sup>49</sup> User fees again filled the gaps.<sup>50</sup>

Seventeen years have passed since a transitional government was put in place to help usher the country out of war. Yet few improvements have been made in the health sector. The majority of Congo's health system is still funded by users themselves through user fees. In 2014, households accounted for 42 percent of all healthcare expenditures in Congo, more than either donor (at 40 percent) or government expenditure (14 percent).<sup>51</sup> End users, already rendered vulnerable by war, poverty, and economic collapse, fund the majority of their own healthcare, if they can access healthcare at all.



However, the problems with the healthcare system in DRC are not limited to access. In a reversal of the normal flow of health investment from administration down to health structures, the user fees collected at individual health structures move up the chain to fund central healthcare administration.<sup>52</sup> In this way, some health centers and hospitals have begun to feed into a broader predatory system, where, in the absence of regular government salaries, end users fund both the local provision of service as well as the central administration.<sup>53</sup>

Compounding this movement of user fees away from health structures is the displacement of medications and medical supplies from public health centers to the households or private pharmacies for private profit. When medications and medical supplies are displaced from public clinics and hospitals, these structures are emptied of the tools necessary for caring for the Congolese population. In this way, the Congolese state and its functionaries actively dismantle the already-limited services that exist. As one Congolese physician explained cheekily, "one doesn't become a doctor to heal people here. One becomes a doctor to have access to a hospital's pharmacy, which they can then divert to their private pharmacy." This statement reflects how the low wages paid to doctors and other public sector workers in Congo drive some to divert public goods for private ends. And still, where user fees render the healthcare system inaccessible and health structures have been dismantled, early mortality is common, <sup>54</sup> and life expectancy remains devastatingly low—59 years for Congolese men. <sup>55</sup>

Aside from contributing to poor health outcomes, the evolution of the Congolese health system from a site of provision to one of extraction has had negative effects on the system itself. As the quality of healthcare offered in public clinics and hospitals has diminished, private structures have multiplied. Some of these structures are integrated into the public health system, receive significant funding from faith-based networks, employ well-trained personnel, and offer quality care; however, these are the minority.<sup>56</sup>

A small number of these informal structures are run by traditional or biomedical practitioners who have received formal training; however, in our experience working in and researching Congo's healthcare system, we have found that the great majority of informal labs, pharmacies, and clinics - which make up the great majority of all healthcare structures in DRC<sup>57</sup>—are profit-making ventures run by untrained (or informally trained) personnel.<sup>58</sup> It is only through a greater regulation of this system—by shutting down fraudulent practitioners and rehabilitating those that have a function—that these dysfunctions can be remedied.

In this context, where much of the public system has been dismantled and much of the private system is undertrained, Congolese seeking healthcare have very few good choices. In eastern Congo, a therapeutic trajectory typically begins with a presentation to a nearby pharmacy, where they explain their symptoms and buy whatever medication is recommended. This is called *auto-médication*. If *auto-médication* is not effective, most will either stay at home or, if funds permit, visit the nearest clinic—a traditional healer or a small, underequipped private clinic. If the medications recommended by these providers do not improve the patient's condition, the patient might then visit a larger clinic or hospital, which are often more expensive and farther away than the informal structures. As pocketbooks empty and the patient's illness worsens, desperation increases with each stop. And yet, as a traditional practitioner in Mangina explained, people "just want to get better. People will go wherever it is that that might happen." 59



Much harm can be done by the medications consumed prior to reaching a formal structure, as well as by the delay in reaching the formal structures. When patients finally do reach formal structures, their illness is often already advanced; rapid and effective intervention is needed. Instead, they arrive to find medications, diagnostic techniques, and motivated personnel to be lacking. Poverty and extractive practices combine here with catastrophic consequences, giving rise to the Swahili phrase, "in Congo, we don't stay long above the soil [hatubaki muda mrefu yulu ya udongo]."

It is this healthcare system that the Ebola Response encountered when the tenth epidemic began in North Kivu in 2018. With healthcare prohibitively expensive and healthcare practitioners ineffective, much care of the sick and dying happened at home, and illness and early death were pervasive. Given the dilapidated state of the health system, the Response did not attempt to support it to manage Ebola. Instead, it developed a parallel health system through which Ebola would be managed.

# The Building of a Parallel Health System

Congo's tenth Ebola outbreak occurred in an area called the Grand Nord. This area has long been home to a cohesive and prosperous business elite, rooted in the majority Nande community. Beginning in the 1980s, entrepreneurial businesspeople pioneered trade networks with the Middle East and China. Mobutu's central government was perceived at best as an impediment, at worst an outside oppressor to these local initiatives.

During the Second Congo War, between 1999 and 2003, this area was home to the RCD/K-ML rebellion, which benefitted from the support of these cohesive business and political elites. With the reunification of the country in 2003 and the first democratic elections in over 40 years in 2006, this unity began to fray, resulting in the violent competition for power. A key player was the Allied Democratic Forces (ADF), a Ugandan Islamist rebellion, which had become embedded within local communities. When the Congolese government launched an offensive against the ADF in 2014, large scale violence ensued, with the ADF, but also other belligerents, engaging in massacres of civilians. <sup>60</sup> As of the publishing of the second CRG report on this conflict in 2017, 800 people had been massacred and 180,000 displaced. These figures have only risen in recent years, as the violence continues. The region's long history of political oppression and of violence—at the hands of the central government, or by local armed groups sponsored by neighboring countries—profoundly influenced local understandings of and reactions to the Ebola Response. As was the case in West Africa, fear predominated. <sup>61</sup>



# Mangina: May - July 31, 2018

According to our research, Ebola likely began taking lives in North Kivu as early as May 13, 2018.<sup>62</sup> Eleven interviews with various healthcare providers and community leaders in Mangina, the town in North Kivu in which the epidemic was eventually declared, all confirmed that a young man in Mangina came back from several weeks on a rural farm a day's walk from town with an infectious, febrile disease characterized by significant diarrhea, which turned hemorrhagic in his last days. Within several days of his arrival at the Mangina Referral Health Center, he died. Within a week of his death, his twin brother, with whom he lived, developed similar symptoms, and died, also at the health center. Eventually, five people in the household would die of this mysterious illness. Other people from the community would become infected at the same health center.

When the deaths first began, the mayor [bourgmestre] of Mangina, together with several other community leaders (neighborhood chiefs, religious leaders, and nyumba kumi), began encouraging traditional measures of infection control. Though they had no formalized health training and knew nothing about this particular disease, they recognized it as infectious and worked to prevent transmission. First, they encouraged families to wrap their deceased in plastic sheets [decalo] to reduce the spillage of bodily fluids. This had long been a practice for bodies that were deemed "dirty," such as those who had drowned, were found decomposed, were killed in massacres, died of cholera—in short, any bodies that could pose a health risk to funeral goers. The traditional leaders also encouraged families to carry their deceased straight from the hospital to the cemetery. As a result, those presumed to be infectious were buried in small graveside ceremonies, with larger wakes held in the community only after the infectious risks posed by the bodies of the deceased had been mitigated. In an effort to protect themselves, community members took on their own precautions too: hand hygiene increased; many families practiced some version of social distancing; traditional methods of preventing diarrheal illness were employed.

Impressively, this mostly illiterate farming community put into place many of the measures necessary to control Ebola transmission without any aid from health workers or health authorities. As a result, community transmission was relatively low, and the disease simmered for months without gaining epidemic proportions. However, in an ironic twist, the health center, which had instituted so few infection prevention and control (IPC) measures, became a disease hotspot. In the transmission chain that our ethnographic team constructed of the epidemic prior to its declaration, the Mangina health center was the site of transmission for the majority of cases. When those who did contract Ebola were brought to the hospital, they infected other patients as well as some healthcare workers, and the disease spread.

The healthcare providers who had been in Mangina during this time, both the nurses and physicians that we interviewed, spoke of their lack of knowledge about Ebola, as this was the first Ebola epidemic in North Kivu. In multiple interviews, these providers echoed: "We had never seen Ebola, and it was only one line in our textbook." Despite nine previous epidemics in the country, in which Congolese physicians and scientists had conducted foundational research on the disease, the symptomatology and clinical course of Ebola had not been included in their formal education. This failure of the Congolese medi-



cal education was exacerbated by the fact that early death has become normal in Congo. As one physician who remembered the initial cases insisted, "There are always deaths at hospitals here. At first, we did not notice anything strange [on n'a constaté rien de bizarre]. We had no reason to call the authorities." 66

By the middle of July, some 5-10 people a day were dying with similar Ebola-like symptoms in Mangina, and the healthcare workers eventually recognized that the disease must be infectious. "At some point, they all had the same symptoms, and they had a fever." Near the end of July, they created an isolation room within the health center. Despite creation of this isolation room, they did not increase personal protective equipment (PPE) or IPC measures, and transmission within the health center continued. As one nurse at the Mangina Referral Health Center said, "Back then, gloves and masks were not part of medicine. We had chlorine tabs in the pharmacy, but we didn't know how to use them." 68

Additionally, despite their recognition of the infectious nature of the disease that was ravaging their communities, they did not alert health authorities. One nurse justified their actions thus: "How had the authorities ever helped us before?" The authorities that the healthcare practitioners in Mangina should have alerted were the same authorities who had failed to step in when the salaries of nurses in Mangina disappeared for several months prior. To

Eventually, the mayor [bourgmestre] of Mangina—a civilian with no health training, who had led the initial efforts at infection control in the community—became frustrated at the health center's lack of action and called the health authorities himself to demand an investigation. Several days after he made the call, six Ebola tests were sent to Kinshasa for analysis.



### August 1, 2018 - May 2020

On August 1, 2018, the then-Congolese Minister of Health declared the beginning of Congo's tenth Ebola epidemic. Because Mangina was an area, like Beni, that had endured attacks and massacres since 2014, the tenth epidemic inspired significant fear in Response staff from the beginning. Never had Ebola been managed amidst an active armed conflict. As Congolese health authorities from Kinshasa (many of whom had never visited the region), UN agencies, and humanitarian organizations poured into Mangina, the new arrivals discussed dual threats to their safety: that posed by Ebola and that by the recent massacres in the area.

Initially, the epidemic management plan rolled out in Mangina was firmly rooted in public health best practices: healthcare agents were trained in the early identification and isolation of Ebola-positive patients; community members were trained in contact tracing (the daily monitoring of people who have come into contact with an Ebola-positive person for 21 days, with the goal of isolating them rapidly if they fall sick); and everyone was given information about basic measures to prevent Ebola transmission, including handwashing and safe burials. Given how much progress had been made in West Africa on the development of new therapeutics, experimental vaccines and treatments also comprised one arm of the Response from the beginning. Within two weeks of the declaration, Merck's rVSV-ZEBOV vaccine, which had been trialed in West Africa, was being administered in Mangina. mAb114, an experimental treatment molecule that had demonstrated encouraging results in animal models, was being administered to those who tested positive for Ebola. Because neither vaccines nor treatment had been licensed yet for Ebola,<sup>71</sup> a set of compassionate use protocols was developed to guide the ethical use of these experimental vaccines and therapeutics.<sup>72</sup>

Initially, the management of the tenth epidemic might have seemed to be off to a good start. Many experts had been flown in, and the cases seemed confined to Mangina. The few that had presented at the Beni hospital had come directly from Mangina, and the Response assumed that appropriate infection control in the health center would prevent future flight. In the community, things were proceeding as they had in prior epidemics, with sensitizers circulating with megaphones disseminating the messages that "Ebola is real" and "Ebola kills." 73 In short order, it became obvious that the fear-based public health messaging in this region that had endured so much historical oppression and violence was having detrimental effects. 74 "The town emptied," a physician who had been in Mangina at the time remembered. "People were told that there was a virus in town, that the virus killed you, and that there was no cure—so people left. It was like war-time—they packed their things and became refugees in far-away villages, hoping to escape the virus."75 When the Response then started to talk about experimental vaccines and possible treatment, people's fear turned to mistrust. "They told us that nothing could be done if you got Ebola, and then they said that everyone with Ebola should go to be treated, and [get] their family vaccinated. People were confused. Why had they said nothing could be done and then said to come and get vaccinated? People asked, what was in the vaccine? What were they going to inject in our bodies?"<sup>76</sup> recounted a community leader in Mangina. Driven by fear and mistrust of the Response, many left Mangina, spreading Ebola across the region.<sup>77</sup>



Across the region, the Response played catch-up, recruiting and training surveillance teams after new Ebola cases had been found. In the larger cities, it built Ebola Treatment Centers—but the community in the immediate vicinity of these centers had not yet seen an Ebola case, and many rumors developed about the fabrication of Ebola cases to populate these empty centers. A religious leader in Beni explained, "You must understand—this region had never seen that many *Kinois* [people from Kinshasa] or that many humanitarians. From the perspective of many people from the Grand Nord, all they saw was wealthy foreigners [batu wa nje] who talked about a disease that we had not yet seen with our own eyes. We have been massacred for years and no one came; and now they came and built centers for a disease that had not yet arrived. People said, there must be something else [kitu kingine] with this disease."<sup>78</sup>

In mid-October, Pamoja Tulinde Maisha (PALM), a randomized control trial (RCT) designed to compare four promising treatment molecules, was launched. While our research found the trial procedures ethically sound, some Congolese denounced the fact that even if a cure to Ebola was found, it would not necessarily be made available to them, given the often exorbitant costs of newly patented medication. One activist said, "We know that they are not developing these treatments for us. This is so they can treat any white people [muzungu] who get infected with Ebola. In West Africa, they flew out the white people [muzungu] and saved their lives while the local people suffered and died. When have Blacks [les noirs] ever received expensive medication to save their lives? We should not be their guinea pigs."<sup>79</sup>

In November 2018, armed men attacked a UN military base in Beni. While it is not clear whether the attack targeted the Response, it marked a paradigm shift in the way that the Response understood security in the region. There had been several other minor attacks directed towards the Response prior to this, and in this particular attack, no Response staff or property was damaged. And yet, this attack was the closest contact that many of the foreign staff had had with violence. The WHO, the UN, and other humanitarian agencies evacuated many of their nonessential staff, and the central offices of the Response were moved to Goma, where they would stay for much of the rest of the epidemic. When on-the-ground Response activities resumed in the Grand Nord, new demands for military escorts were made. In the name of safety, UN and government soldiers began accompanying some Response teams into communities. Not all agencies and organizations demanded or allowed military accompaniment; however, the local population often had difficulty distinguishing between the various agencies, and grouped anyone working in the region on Ebola—whether officially as part of the Response or not—as having participated in the militarization of the epidemic. It is just criminal, one activist in Beni said about armed men accompanying the Response. They are paying the same soldiers who terrorize us at night to protect them. And then, when they come to our homes with those men with guns, they expect us to believe that they want to save our lives?

As in West Africa, relying on structures of violence to protect one group often put other groups of people in danger.<sup>83</sup> In a region where government troops, UN troops, and other armed groups have all committed offenses against the population, no combatant was considered neutral, and many were seen as criminals. By using soldiers that many saw as abusive to protect themselves, the Response implicitly condoned or downplayed



the previous abuses that these groups had committed. It also suggested to local people that the safety of the Response staff was more important than their own safety—a hierarchy of lives that constituted another manifestation of the structural violence in which the Response participated.<sup>84</sup>

Despite the population's loud critiques of the militarization of the Response, it continued. At one of the strategic planning meetings at the end of October 2019, a Congolese physician from Kinshasa working for the Response justified this practice: "Militarization and community engagement happen on different timelines. We must use militarization to control the epidemic now; and we can use community engagement to change the population's behavior so that we can control the epidemic in the future."

# The "Foreignness" of the Response

Overall, the Response was experienced by Congolese in Ebola-affected areas as a foreign entity—imposed from outside, with priorities external to those of the community, and led by people who were not from the Grand Nord. However, as everywhere, foreignness was often more about degrees than absolutes. The Response personnel included non-Congolese from Europe, North America, and West Africa. It also included a number of Congolese nationals from other parts of the country, in particular from the capital, Kinshasa. Besides skin color, language was often the marker by which people from the Grand Nord evaluated and ascribed degrees of foreignness. For instance, West African Response personnel were identified by their inability to speak Kiswahili or Kinande, the two main languages of the region. Similarly, Response workers from the capital, Kinshasa, were identified by their preference for Lingala instead of Kiswahili.

Two important elements are present here: first, the gap in understanding of the local context that a Congolese physician from Kinshasa displays. Fueled by a language barrier, so as well as derogatory views about the rural population, often referred to as "uneducated [pas éduqué]" in official meetings, so this divide between urban Congolese from outside the Grand Nord and the local population presented itself in various ways throughout the epidemic. Because they felt judged and misunderstood, the local population often referred to them as "foreigners [batu ya nje]." The other element that the above quotation from the physician in the Response makes clear is the idea about the timescale on which the Response operated—a positive Ebola case had to be brought to the ETC even if that required military forces, burials had to be conducted in 24 hours, contact lists in 72 hours, always with an urgency to "get to 0." This emphasis on getting to zero—eradicating the final remaining cases—rarely took a broader view of what long-term impact these containment-at-whatever-cost mindset might have on the possibility of controlling the epidemic in the future, or on humanitarian dynamics in the region more broadly. So



In February 2019, after months of increasing tensions between the Response and the population, armed groups attacked Ebola Treatment Centers in Katwa and then Butembo. The Médecins Sans Frontières (MSF) sections that had built and had been operating the centers evacuated their personnel and suspended their operations indefinitely. Eventually, another organization, ALIMA, rebuilt and reopened the Katwa ETC, and with the aid of WHO, the Congolese Ministry of Health reopened the Butembo ETC.

The assumption of an operational role with the Butembo ETC solidified a shift in the WHO's role in the epidemic. Because the WHO had been sharply criticized during the West African epidemic, oit had taken a more hands-on role from the beginning of the tenth epidemic. However, it had never before taken on the role of day-to-day operations that was required when it partnered with the Ministry of Health to reopen the Butembo ETC. No longer was the WHO a neutral advisory body that advised the Ministry of Health on how to effectively manage Ebola treatment; now, it was in partnership with the Congolese government, intimately involved in hiring and paying staff, securing medication and food, and other daily tasks. This was proved to be both a stretch on WHO capacity and also a conflict of interest, as the WHO was now supporting a government that often contradicted its own recommendations of best practice. Whether because of the WHO's lack of experience in operations or because the WHO deferred to the government in establishing the ETC's policies, the ETC in Butembo had the least capacity to deal with complex clinical care of all of the ETCs in the Grand Nord. Our interviews with staff in this ETC cited multiple examples of patients who died due surgical or obstetric emergencies that other ETCs treated effectively.

In the time period leading up to and directly following the ETC attacks, the Congolese population had grown increasingly suspicious and mistrustful of the Response. From the fear-inducing health messages at the beginning of the epidemic to the ethical challenges posed by the RCT to the militarization, the Response continued to function in a way that appeared to many Congolese that it was more concerned with stopping the epidemic than with the well-being of the local population. A member of a civilian political movement gave voice to this sentiment, "They say they are here for us; but in reality, they are here to make sure that Ebola doesn't go to Europe or America. If they cared about us, they wouldn't bring the military to our homes. If they cared about us, they wouldn't erect more barriers [handwashing stations] where the military can hassle us. In Congo, we die of hunger; we die by machete; at least, may they leave [wangeenda]. We will die of Ebola but we will be in peace." Par Importantly, the self-serving nature of some of the Response activities was affirmed by some humanitarians working in the region. An MSF chief project coordinator was quoted as saying, "The people tell us, you have not come here because we are sick but because we are contagious. And they are right. We have come for fear of a pandemic." Par Importantly.

Where the community questioned the fundamental motivations of the Response, <sup>96</sup> the efficacy of containment measures was reduced. Communities chased "foreign" vaccination and surveillance teams from their communities. Many with Ebola symptoms refused to go to the ETC, instead dying at home. <sup>97</sup> Case numbers surged. <sup>98</sup> Despite advances in clinical care, case fatality rate remained stubbornly high. <sup>99</sup>



As with other epidemics before West Africa<sup>100</sup> and on a wider scale in the West African epidemic,<sup>101</sup> the Response relied heavily on its social science arm for communication with the population, the Cellule d'Analyse en Sciences Sociales (CASS). In the tension-filled months of February through May, CASS worked to help give the community a voice in the Response. And yet, fundamentally, the Response understood epidemic management to be something that experts, not communities, did. At its base, the Response had been designed on a model of one-way communication: information flowed from the Response to the community and rarely the other way around.<sup>102</sup> As a result, CASS's retrospective surveys on perceptions of disease did little to appease a population who looked at the Response and saw only foreigners—international experts and physicians from Kinshasa who did not see the community as possessing its own strengths in epidemic management.<sup>103</sup>

Amidst the tension between the population and the Response, three Ebola cases appeared 300 miles from the epicenter of the epidemic, in the provincial capital of Goma, and another set of cases were diagnosed across the border in Uganda. In response to this geographic spread, on July 17, 2019, WHO declared the epidemic a Public Health Emergency of International Concern (PHEIC).<sup>104</sup> Although the outbreak in Goma was short-lived, the PHEIC label would stick, bringing with it more funding, and heightened international pressure to stop the epidemic.<sup>105</sup>

As the Response fought its battles with the community, clinical advances continued to be made within the ETCs. In March, a new treatment manual was published,<sup>106</sup> and by the summer it was being followed religiously in ETCs with improved outcomes. In August 2019, an interim analysis of the PALM study (of Ebola therapeutics) highlighted the importance of early treatment: case fatality rate was reported to be 19 percent for those who came to a treatment center within one day of symptom onset. In contrast, even with aggressive resuscitation and administration of the novel therapies, almost half of people who had symptoms for five days before seeking treatment died.<sup>107</sup>

As with the treatment domain, advances were also made on the prevention side. For months, vaccination proceeded by the ring strategy, whereby only healthcare providers and those who had close contacts with someone diagnosed with Ebola were eligible for vaccination. Discussions were ongoing about how to increase the supply of Merck's rVSV-ZEBOV so vaccination could be open to the entire population living in the Ebola-affected regions in North Kivu and Ituri. However, given various obstacles to vaccine expansion with rVSV-ZEBOV, MSF and Johnson & Johnson brought a second vaccine—Ad26.ZEBOV/MVA-BN-Filo—to the region and began testing this two-dose vaccine in November 2019.



At the beginning of November, a lull in cases brought some hope that the end of the epidemic was near. However, as the government army ramped up its offensive against the ADF armed group, some people living in the rural areas of Beni fled their homes. While this was not the mass population movement that the region has previously seen, enough households were displaced to interrupt Response activities, and case numbers again increased. At the same time, massacres of the population—whether by ADF, government soldiers, or another armed group—also increased in November. Between November and February, 338 people in and around Beni were killed in such massacres. While these massacres did not directly affect Response activities, they put in sharp relief the fact that Ebola was merely one threat that Congolese faced on a daily basis. A community member in Beni described the situation thus: "ADF attacks us from the east, and Ebola from the west. From both sides, we fear being exterminated [tunaogopa kuwa exterminé]."<sup>111</sup>

Eventually, despite all of the interruptions and challenges, case numbers began to dwindle in January 2020. Finally, on June 25, 2020, North Kivu was declared Ebola-free—although another new epidemic, the country's eleventh, has already emerged 1200 miles to the west.

# The Response and the Community

Having sketched the overall contours of the tenth Ebola epidemic, we will now dive deeper into describing the parallel Ebola system and its effects on the community and the healthcare system. To begin, however, we will trace the relationship between the humanitarian industry more generally and the Congolese population, for the idea of a parallel system has roots in humanitarian logic.

For several decades, the Congolese state has not had the capacity, nor, arguably, the will, to provide for its citizens. As a result, living conditions in Congo are dire: 43 percent of children in Congo are malnourished, and less than half of homes have access to clean water. In this context, humanitarian organizations have stepped in to provide basic services. Often, they target a specific crisis in what are called "vertical programs": sexual violence, HIV, TB. In so doing, they ignore the inequalities that have limited life expectancy in the region for decades: food insecurity, limited access to clean water, dysfunctional health facilities, and war. In Congo, the mismatch between humanitarian agendas and the desires of the population have, at times, resulted in demands for international actors to leave, citing more harm than good.

When the Response arrived in the Grand Nord in 2018, it initially adopted a narrow, compartmentalized approach. One expatriate working with the Response explained it thus: "War, hunger, joblessness, these have existed for decades, and they are political problems. We are just here for Ebola. We are here for a medical problem." This, even as it has long been argued that Ebola is fundamentally a disease of poverty: Ebola has only ever emerged in areas characterized by subsistence hunting and agriculture, limited access to clean water, local healthcare providers who lack basic training and personal protective equipment, and deep socioeconomic inequality; and when Ebola was treated in the U.S. and Europe during the West African epidemic, it was easily contained. Because many members of the local population recognized Ebola's relationship to poverty, they were frustrated by (and skeptical of) the Response's belief that it was possible to treat Ebola as "a medical pro-



blem." And yet, for the most part, the Response maintained almost surgical precision—they were not there to build the skills of community health workers or to durably add triage systems to healthcare facilities—efforts that would have minimized transmission in this epidemic and potentially prevented the next. Rather, their temporality was short-term: the plan was to get in and get out. As a result, improvements to structures and systems were temporary, any trainings surface-level.

In the end, the Response operated across two sites: in Ebola-related public health campaigns in the community and in the Ebola-specific triage and health facilities that it erected. In both settings, its goal was to remove possible Ebola cases as soon as possible from the community and to place them into an externalized, parallel Ebola system where they would be tested, and if positive, treated for the disease.

In this section and the next, we describe in detail how this parallel system actually functioned. Throughout, we highlight the ways in which the external nature of the Ebola system undermined containment efforts and exacerbated structural, if not physical, violence in the region. We begin in the community, where the Response worked mainly through sensitization, contact tracing, safe and dignified burial, and vaccination efforts.

### Sensitization

The most contact the local population had with the Response was through its sensitization campaigns. Designed to educate people about Ebola's symptoms, modes of transmission, and consequences, the sensibilization arm of the Response was largely comprised of men and women who circulated door to door with five-minute messages about the disease. Few of these sensitizers had a health background; rather, most were traders or farmers or teachers who had undergone a two-day training about the disease, in which they were encouraged to give simple messages to the population. One motivation given for this was low literacy rates. One Response staff member put it thus: "Our job is impossible—we must teach an illiterate population the virology of a virus about which much is unknown. The only way forward is in simple messages." And so, education about Ebola was largely limited to commands such as "Do not touch a person who has Ebola," and "Go to the hospital if you are sick."

Surely, in North Kivu, language barriers affected the possibility to transmit nuanced messages.<sup>120</sup> Many people speak Kiswahili and/or Kinande and have only a basic understanding of French. Even when speaking Kiswahili or Kinande, community health workers maintain French words like "vaccin" and "virus."

While those who mainly speak Kiswahili recognize some health-related words in French—"vaccin," vaccination, as a word and a practice is largely accepted—deeper understanding of these concepts is required for people to be able to informed decisions about prevention and healthcare. Where the contracts of sensitizers were measured in days, the time for these discussions was neither taken nor encouraged.



Importantly, also, training for sensitizers was not centralized. UNICEF led this arm of the Response; however, many other organizations developed their own versions of a training curriculum. As a result of the decentralization of the training and the short timeframes in which the Response was working, trainings lacked important details about vaccine efficacy, Ebola's transmissibility, case fatality rates, and recrudescence.

Unfortunately, with a virus as complex as Ebola, the devil is in the details. Through a discussion of five details that were simplified in the sensitization campaigns, we demonstrate how the papering over of these nuances exacerbated the population's sense that the Response was not there for their benefit.

#### Ebola is not necessarily a hemorrhagic fever

Despite clear descriptions of the stages of EVD, from "dry" to "wet" symptoms, <sup>121</sup> the Response initially used training materials that portrayed people bleeding from their eyeballs and vomiting pure blood. <sup>122</sup> In reality, at the beginning of the illness, Ebola presents with nonspecific symptoms that resemble those of malaria, typhoid fever, and Shigella—all infections that are significantly more common in the region than Ebola. It is only in the later stages that some patients develop the visible bleeding that was displayed on the initial sensitization materials. In fact, less than 50 percent of patients bleed at all, and, in those who do, the bleeding often presents subtly. <sup>123</sup> As a result of its often-subtle presentation, even advanced practitioners find the differentiation of Ebola from other diseases more common to the area difficult.

By simplifying Ebola's symptomatology and calling it a hemorrhagic fever (even in trainings with healthcare practitioners), the Response silenced the first part of the disease, with its "dry" symptoms. As a result, neither the population nor healthcare providers of the information that they needed to diagnose the disease in its early stages—and late recognition of the disease contributed both to transmission as well as to poor outcomes. Due to work by CASS, sensitization materials were changed in mid-2019 to minimize the hemorrhagic aspect. At the level of health structures, the Response made efforts to improve the case definition, and, in partnership with MSF Epicenter, developed a triage tool that might catch Ebola in its early stages (in press). And yet, as of March 2020, sensitizers continued to talk about vomiting and defecating blood [kutapika na kunyamba damu] as they circulated through households. When asked why, several stated that this was the simplest way to relay the message. The rampant circulation of such inaccurate messages about Ebola meant that the population did not recognize anyone who was not actively bleeding to potentially have Ebola. This poor understanding of the disease led to very delayed presentations, increasing the mortality of the disease. It also created significant reticence from the population when the Response attempted to test or treat people in the early stages of Ebola. The Response, in turn, met the community's reticence by forcing patients to seek treatment, further exacerbating distrust.

#### • Ebola has a low overall rate of transmission

Throughout the DRC epidemic, sensitization messages stressed that anyone who touched a person with Ebola would fall sick and likely die. This fear-based messaging is frankly inaccurate. Despite the Hollywood movies that portray otherwise, Ebola is "highly infectious but not contagious," meaning that while only a



small amount of the virus is necessary for transmission, the overall rate of transmission is relatively low. This explains why epidemics prior to 2014 remained quite small and were stopped with simple public health measures of prevention. The overall estimated household secondary attack rate (SAR) of Ebola is a mere 12.5 percent, meaning that even if a person with Ebola stayed at home to be cared for by family instead of going to a healthcare facility to be treated in an isolation room, the average risk to other household members of developing Ebola is a mere 12.5 percent. Obviously, risk is highest for contacts exposed to infectious body fluids, with an estimated SAR of 48 percent. However, a SAR of 48 percent means that even among those who had the most intimate relationship to the sick, nursing them as they vomited and cleaning up after their diarrhea, less than half would contract the virus. Touching a patient with Ebola did not immediately lead to transmission: some people in contact with Ebola-positive patients contracted Ebola, but, importantly, the majority did not.

If people could touch infected body fluids and not become infected, as the Response had guaranteed, could any of the Response's messages be trusted? Using the phrase "the Response and their lies [bongo wao]," they pointed out other areas where they perceived the Response to be lying, such as providing treatment in the ETCs. In this way, as it disseminated misinformation about Ebola's contagiousness, the Response ultimately undermined its efforts in other areas. In addition, as it incorrectly presented the ETC as the only safe option for the families of the sick, the messaging erased other possible locations for Ebola care. Presented with only one available choice, families felt like the ETCs were forced upon them, again finding themselves in conflict with the Response.

#### • Ebola is only very rarely transmitted through bushmeat consumption

While it is true that Ebola is a zoonosis, and that spillover from reservoir to humans likely occurs during the preparation of infected animals to eat, transmission of Ebola through handling of bushmeat is likely an exceedingly rare event. Ebola epidemic has a single spillover event, compared to hundreds, thousands, or tens of thousands human-human transmission events. In previous epidemics, the bushmeat consumption narrative in Ebola prevention has been problematized. As this previous work states, by portraying bushmeat consumption as a "cultural act," this narrative erases the pressures, including international trade policies, that drive bushmeat consumption in the first place.

Unfortunately, during this epidemic, sensitization materials continued to focus on bushmeat consumption as a major driver of transmission. In addition to being inaccurate, in North Kivu, where food insecurity is at "crisis" levels,<sup>132</sup> and bushmeat consumption plays a central role in subsistence agriculture and hunting, the message "Do not eat bushmeat. Bushmeat has Ebola," denied people vital sources of protein and livelihood. In Congo, communities in and around Mangina who had followed the Response's recommendation to stop eating bushmeat spoke of crushing food insecurity in the household. Importantly, when these households then resumed consumption and did not contract the disease, they attested to having lost trust in the Response. For these households, the inaccuracy of the bushmeat narrative proved that the Response were "jokers [blagueurs, *pas sérieux*]."



#### Ebola is only rarely transmitted through sex

While fragments of the Ebola virus are detectable for some time in seminal fluid and vaginal fluid of survivors, <sup>133</sup> genital secretions have never been proven infectious in laboratory studies. <sup>134</sup> As a result, sexual transmission of Ebola remains poorly understood. Despite more than 10,000 survivors from the West African epidemic, <sup>135</sup> only a handful of cases of sexual transmission have been recorded (Lee and Nishiura 2017). <sup>136</sup> While no population-level studies exist, virologists and epidemiologists extrapolate from the low incidence of new flares of disease in West Africa to conclude that "[sexual] transmission leading to disease is uncommon". <sup>137</sup> Thus, the emphasis that was placed on sexual transmission during this epidemic—from the featuring of sex on posters about transmission to sex-shaming discussions with survivors during their monthly follow-up—is not scientifically accurate.

Given Congo's long history of being over-sexualized by Westerners,<sup>138</sup> the emphasis on the sexual transmission of Ebola was met with significant skepticism. In our ethnographic research, people describe seeking out sexual relationships with Ebola survivors "to prove the Response wrong [faire mentir la Réponse]." Clearly, misrepresentation of the role that sexual transmission played in the overall epidemic worsened the breakdown in the relationship between the Response and the population. Like with the other fear-based messages, the Response's overstatement of the likelihood of transmitting Ebola through sex only served to decrease its legitimacy in the eyes of the population.

#### Ebola carries a possibility of recrudescence (relapse)

Throughout the epidemic, the Response circulated the message that survivors cannot fall sick with Ebola a second time. The motivation behind this statement was two-fold: first, the Response wanted to reassure survivors that they were now safe, on the other side of their life-threatening illness; secondly, given the stigma around Ebola, the Response wanted to facilitate the survivors' reentry into their homes and communities. In the end, it is a mostly true statement—for the most part, Ebola survivors do not fall sick again. However, recrudescence, or relapse, is a known phenomenon. It was both documented in West Africa, and in Britain, with a survivor of the West African epidemic. Within the first few years of recovering from Ebola, it is possible to fall sick again—with the same symptoms and risks of transmission as any other Ebola case.

Elsewhere, the possibility of relapse would at least be discussed with survivors and the healthcare workers taking care of them. After all, survivors need to know that they should present to a health structure early in any illness that could resemble Ebola and be tested for the disease. And healthcare providers need to know to test for Ebola when a survivor returns with Ebola-like symptoms. Unfortunately, the Response denied both survivors and healthcare workers in the region this information. In two separate conversations with WHO staff charged with communication with survivors, they stated that they had made the decision not to tell survivors or healthcare providers about the possibility of recrudescence because they did not want to inspire fear. "How would this population, who cannot read, react to being told that they could get Ebola again?" one WHO staff asked.<sup>141</sup> Ironically, it was the silencing of information about recrudescence that actually inspired significant fear—many survivors had heard of other survivors falling sick again with Ebola and did not understand why. The silence surrounding recrudescence also had devastating consequences: in



late 2019, when a case of likely recrudescence was encountered in Aloya, there was significant delay in his diagnosis, leading to a transmission chain of 82 confirmed and probable cases.<sup>142</sup>

Dealing with uncertainty in public health is difficult. Some recommend the use of risk scales (e.g. low-medium-high) or modal verbs (e.g., might, could) to craft honest messages that are also scientifically accurate. In the areas of HIV, drug use, and sex education, harm reduction principles have proven both respectful and efficacious. Repeatedly in our ethnographic work, Congolese asked for accurate, detailed messages that would enable themselves to better weigh the risks of Ebola in their everyday lives and, having done this, make their own decisions about how to protect themselves and their communities from the disease. An older, illiterate woman in Butembo put it thus, "Even though we do not know how to read, we have sense. We regret that they treated us like children, who cannot understand. How are we supposed to make educated decisions if we do not have the information?" 145

Surely, using harm reduction techniques requires some relinquishing of control, for it is true that, if provided accurate information about Ebola's low rates of contagion, the Congolese population still might not have been the perfect patients—some might have weighed the risks of transmission with their mistrust of the Response chosen to treat their family members at home. Importantly, however, this would have been an informed decision made in full awareness of the risks their actions carried, as opposed to an uninformed reaction to fear-based messaging. While the dissemination of nuanced public health messages in multiple languages during a crisis is a very difficult task, harm reduction strategies provide an alternative that could, perhaps, move humanitarian efforts towards more compassionate, and more effective, intervention, which was oriented towards collaborating with the community instead of dominating it.

## **Contact Tracing**

In addition to sensitization, the Response also entered the community for the tracing of contacts of those who tested positive for Ebola. From the beginning, contact tracing was poorly accepted by the community. Despite the existence of *relais communautaires*, community health workers that had been institutionalized during the Mobutu era (see above), the Response employed and trained new teams for contact tracing. Surely, this frustrated the existing *relais communautaires*, who, knowing that their positions were codified in law as unpaid positions, had worked for years without compensation for the sake of their communities. However, it also created significant suspicion within the community. Why were strangers coming in from the outside to do a position that the community had long filled? When contact tracers began asking for the names of those with whom infected people had had contact, suspicious community members gave fake names or remained silent so as to protect their families and neighbors from these "strangers" and the Response that they represented. The population's flight from the tracers significantly affected the efficacy of contact tracing. A CDC report states that "the contact tracing data reviewed for the period August 1, 2018 to December 31, 2019 revealed that only 46 percent of EVD cases were listed as known contacts." The



Even when contacts were identified, they often fled when they heard they were being sought out by the Response. A group of women in Beni encountered by our ethnographic team asked, "Have you ever seen physicians come to pick up [venir récupérer] a patient at his house? No, nowhere [nulle part]." As the lists of "not seen" and "never seen" contacts increased, the Response doubled down on its efforts. More pressure was placed on contact tracers, and more militarized language began to be used. At a strategic planning meeting for the Response in October 2019, a presentation was given on the importance of reducing the time it took for symptomatic patients to arrive at a health structure. After presenting data that linked shorter delays to less secondary transmission, the speaker concluded with the adage "strike hard, strike early." Amongst themselves, contact tracers often referred to each other as "soldiers [soldats]." This nomenclature was formalized in a banner that hung in the Response's meeting room in Goma, which read, "Thank you for your sacrifices, brave soldiers of the Response [Merci pour les sacrifices consentis valeureux soldats de la Réponse]." Pitting Response staff against the community, this symbolic militarization of contact tracing teams only served to increase the community's distrust of the Response.

From the community's point of view, the more aggressive contact tracing became, the more it inspired fear. While the length of contact lists increased near the end of the epidemic,<sup>150</sup> contact tracing was never fully accepted. A chief in Butembo described the problem thus: "People have much greater fear of the Response's teams than they do of the virus." Again, here, the resort to structures of violence only served to undermine the Response's rapport with the community. In the future, using the existing structures, in Congo, the volunteer relais communitaires would go a long way toward creating inroads with the community.

### Safe and Dignified Burials

A third axis of community-Response interaction surrounded burials. Because the bodies of people with Ebola remain infectious after death, the burial of infected individuals can be a site of transmission. As a result, in previous epidemics, anthropologists have worked with humanitarian actors to develop protocols for "safe and dignified burials," which are meant to take into account the cultural aspect of funeral practices while also burying the infectious body in a safe manner.<sup>152</sup>

In previous epidemics, anthropologists have suggested techniques to minimize disruption to the burial process including burials performed by family members with transparent body bags and minimal personal protective equipment (PPE) (after the original placement of the body in the body bag +/- casket). In Uganda in 2007, the WHO had already begun conducting family-centered burials using transparent body bags to allow the family members to see, to witness the person being buried. And yet, in the tenth epidemic, as in those that preceded it, institutional knowledge did not seem to transfer: it took nearly a year to introduce familial burials and transparent body bags into the official Response strategy; when they were finally introduced, they were heralded as innovations in Ebola care.



Because the Response initially conducted burials without considering the families of the deceased—in the name of security, excluding family members from burials or burying people before notifying their family members—the population was reticent to allow the Response to bury their loved ones. While the population asked for dignified burials, conducted by the family, in which the body of the deceased could be viewed and photographed by the family prior to burial, the Response insisted on conducting the burials itself, with military escorts if necessary. Motivated by a desire to "get to zero" instead of by the well-being of the community, such assertions of dominance over the community further deteriorated the relationship between the Response and the population. As a result, in mid-March 2019, the percentage of confirmed Ebola cases that received safe and dignified burials reached a low of 69 percent.<sup>156</sup>

Ultimately, safe and dignified burials are not actually that foreign to the Congolese community. After all, the Mangina community was already performing a version of safe and dignified burials before they even knew what was killing their loved ones. In the future, recognizing the community's already existing public health efforts—and building on current practices instead of creating something new—would go a long way towards collaborative epidemic management.

### Vaccination

The final aspect of Response-community relations we cover here is Ebola vaccination. When the Response first brought the rVSV-ZEBOV vaccine to Mangina in August 2018, it did so as a further trial of efficacy. Because it was part of a trial and thus had not been licensed, it required a consent process. Initially, the consent process was incredibly opaque, with the consent forms being written in French and then Tanzanian Swahili (which would be unreadable to even literate Congolese). Despite improvements in the consent process, in our household survey conducted in early 2020, nearly 40 percent of households reported that they did not understand the information that they had been given about the vaccine. Aside from being unethical, the opacity of the consent process created significant suspicion around the vaccine. People felt that the risks of the vaccine were being intentionally hidden from them; they also doubted the vaccine's efficacy—for if it were effective, why was it still under trial?

If the consent process opened the vaccine up to suspicion, the severity of the side effects of the vaccine—fevers, muscle aches, and profound fatigue—exacerbated the situation. Fearing the significant side effect profile, which affected many at the dose that was initially given,<sup>159</sup> some Congolese refused the rVSV-ZEBOV vaccine. Others recognized that many of the vaccine's side effects were also symptoms of Ebola and feared that they were actually being injected by the Ebola virus itself instead of a vaccine to prevent the virus; they also refused to be vaccinated.<sup>160</sup>



While many refused to be vaccinated, others who wanted to be vaccinated found themselves ineligible. At the beginning of the epidemic, pregnant and breastfeeding women and infants under the age of one year were excluded from receiving the vaccine; neither the safety nor the efficacy of the vaccine had yet been tested on these groups. Due to significant advocacy efforts by the CASS team, this policy was changed in June 2019;<sup>161</sup> however, many mothers and their children had already been affected at this time.<sup>162</sup> If the research protocols excluded some from vaccination, ring vaccination strategy, which limited vaccination to the contacts of those who tested positive for Ebola, excluded others. For many, this meant that they simply were not vaccinated. For others, this meant that they paid a kick-back or sexual favor to vaccine teams to be included.<sup>163</sup> Eventually, with transition from ring vaccination to geographic vaccination, more people had access to the vaccine. Importantly, however, in our ethnographic research, some healthcare providers, especially traditional practitioners and women who had been excluded early in the vaccination campaign, reported being unvaccinated. This posed a risk for their health, as well as that of the health structure.

Vaccine acceptance rates were as low as 26 percent in some regions even late in the epidemic.<sup>164</sup> In a geographic area with a population over 2 million, only 303,905 people were vaccinated with rVSV-ZEBOV (208,993 in North Kivu). In our survey, 41.2 percent of households in Ebola-affected zones lacked even one vaccinated person. Among households that reported vaccination, an average of 2.3 people or 37.1 percent of household members had been vaccinated. While the Response took measures to improve the population's acceptance of the vaccine, some of the most basic suggestions, such as offering the vaccine at health centers, where healthcare providers who had been vaccinating communities' children for decades, were ignored.<sup>165</sup> Even at the end of the Response, the vaccine continued to be offered external to the health structures and he-

alth personnel that the local population trusted.

Ebola is, now, a vaccine-preventable disease; however, this statement assumes the availability of vaccines in the first place. Despite MSF's significant advocacy work to increase the production of rVSV-ZEBOV doses during this epidemic, availability to did not significantly increase. Given a lack of progress with rVSV-ZEBOV, MSF worked to bring a second vaccine in for testing. Still in clinical trial, this vaccine was given in and around Goma, with the goal of protecting the Goma population from any further spread. In the end, whether vaccination will become a large part of Ebola efforts in the future has yet to be seen. With rVSV-ZEBOV now FDA approved, mass production could begin so as to preventatively vaccinate the central African population exposed to Ebola; if Ad26. ZEBOV/MVA-BN-Filo is approved, the same could be said of this vaccine, which arguably offers broader protection, as it protects against four strains of the virus, including strains that caused previous outbreaks in Sudan and Uganda. However, both scenarios require pharmaceutical giants to produce millions of doses of vaccine for distribution at very low cost, and the integration of these vaccinations into the health systems in Ebola-affected countries, along with other routine, preventative vaccinations. As this epidemic has proved, vaccination during an epidemic is logistically complicated, expensive, and ineffective. If the political will existed to realize preventative Ebola vaccination in central Africa, this report could be one of the last on Ebola Responses.



In this section, we have discussed the Ebola system as it existed in the community—as an external structure that employed people considered to be strangers to contain a virus that many Congolese understood to be merely one threat to their lives and well-being. It is important to emphasize this latter point—that Ebola was merely one threat to the lives of Congolese in the region. Throughout this Ebola epidemic, massacres continued in the same region affected by the Ebola epidemic. In the household survey we completed in early 2020, 73 percent of households in Ebola-affected zones reported that violence was a bigger concern in their households than was Ebola (Figure 1).

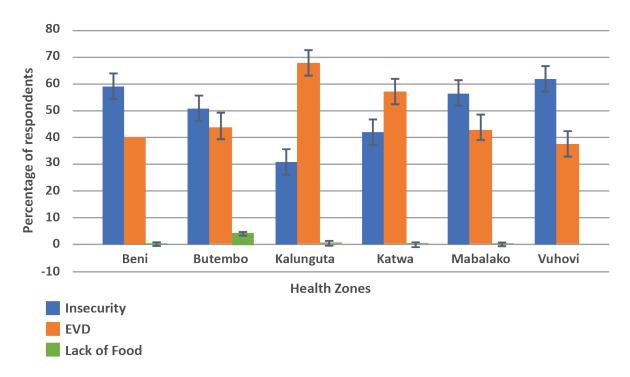


Figure 1. Response to survey question: 'Between Ebola, insecurity, and lack of food, which problem affects your household most?' *Source: household survey.* 

Steeped in an understanding of Ebola as a threat to global health security, and in humanitarian logic of compartmentalized interventions, the Response was so focused on containment efforts that it could not—or did not—recognize the other threats to Congolese well-being. Rather, as it sought desperately to contain the epidemic at all costs, it adopted many of the structures of violence that have historically contributed to death and destruction in the region. In so doing, it demonstrated to the population that "getting to zero" was more important than their well-being. Designed by outsiders, as a parallel structure that sought out the community's advice only as an afterthought, when community resistance threatened containment measures, the Response always remained external to the Congolese community. As a result, the local population sometimes used the word "invasion [envahissement]" to describe the Response's presence in the region. On the reason why the Response felt like such an invasion, such an imposition, one ethnographic team member suggested: "For there to be a response, a question is needed. The Response has come like a response to a question that the people have not yet posed [Pour qu'il y ait une réponse, il faut une question. La Réponse est venue comme réponse à une question que les gens n'ont pas encore posée]." "Waende," many of our ethnographic interlocutors suggested: they should go. People recognized the threat that Ebola posed to their lives, and many still asked that the Response depart.



# The Response and the Existing Health System

In this section, we examine a final element of this parallel system: its structure in relationship to the Congolese health system. As had happened with public health measures in the community, separate clinical structures were built to contain Ebola during this epidemic. The goals of this parallel system were two-fold: to isolate all possible Ebola cases, and to improve outcomes of Ebola-positive patients with specialized care. The parallel Ebola clinical system built for this epidemic was composed of four main elements: (1) triage facilities at all health structures in the region; (2) an active surveillance arm that searched for possible Ebola cases within the region's health structures; (3) temporary transit centers for suspected cases; and (4) Ebola Treatment Centers, at which some suspected cases and all proven Ebola-positive patients were treated.<sup>167</sup>

Importantly, all these structures were temporary, constructed of tarp and scrap wood, and external to the existing Congolese health system. From the beginning, the Response did not believe the existing Congolese health system capable of achieving these goals—nor worthy of the investment necessary for remediation so that it could achieve these goals in the future. In the end, as they had the parallel public health system, the local population rejected the construction of a parallel clinical system. "We already have health centers and hospitals," people said. "Why does the Response not work in these?"<sup>168</sup>

## Triage

Triage is a critical element to any healthcare system. Through triage, healthcare providers can differentiate the very sick from the not-so-sick, intervene rapidly for those who are very sick, and direct the not-so-sick to less emergency-based care. During an epidemic, triage plays a crucial role in infection prevention and control, as those with the signs and symptoms of an infectious disease can be separated from patients with other maladies so as to minimize the transmission of infections within the healthcare system. In general, most Congolese health structures lack both triage areas and personnel with triage skills. As a result, when the Response arrived, one of its first tasks was to create triage facilities, first at the main structures and eventually at the smaller, informal structures. This was crucial to prevent infection; however, the triage structures that the Response built were not full triage facilities, designed not to separate sick from the not-so-sick, or even to separate the likely-infectious from the not-infectious, but rather temporary, limited versions of triage, designed only to identify and remove possible Ebola cases from the health structures.

Small cabins of wood or tarp—or at the small structures, even a table with an umbrella—were erected in front of health structures to house a person whose unique job it was to take people's temperatures and ask a set of questions about their health.<sup>170</sup> If they had an elevated temperature, or triggered an Ebola warning for another reason, patients were instructed to remain outside of the health center until a Response vehicle could pick them up and transport them to one of the Ebola-specific structures. Patients who displayed symptoms of Ebola were physically removed from the health structures that they had come to trust and subsequently displaced to



a tent or tarp-structure, often many miles away, where they would be cared for by unfamiliar people dressed in personal protective equipment that resembled cosmonaut suits.<sup>171</sup> This process created significant distrust in the community. People fundamentally did not understand why the healthcare structures that have always handled other epidemics (e.g. measles, cholera) and other emergencies (e.g. gunshot wounds, difficult births) could not care for Ebola. Fearing this treatment, some patients with symptoms of Ebola remained at home until too late; others sought small, informal structures that did not have triage systems. Importantly, these actions, based in fear, compromised both patients' health and Ebola containment measures.

After a year of witnessing how detrimental this external and extremely limited triage system was for the local population, MSF France established integrated triage and testing sites in three health centers in Beni.<sup>172</sup> Built as proof-of-concept, these sites had the capacity to isolate patients who presented with symptoms of Ebola within the health facility itself, thereby allowing patients to remain near their families, in the structures they trusted while awaiting the results of their Ebola tests. While previously, MSF had seen many patients trigger an Ebola warning and then refuse to go to the Ebola system for testing, since starting this pilot project they reported a 100 percent success rate of transfer to ETCs of positive cases.<sup>173</sup> For the health of the population in general, and especially for the management of an epidemic, local healthcare personnel must be trained in triage, triage facilities must be integrated into health structures, and testing must be performed on site.<sup>174</sup>

### **Active Surveillance**

A second arm of the Ebola system was active surveillance. Because the Response assumed Congolese health providers were incapable of recognizing the signs of Ebola, the Response developed an active surveillance arm to circulate through health structures and search for patients who might meet the criteria for testing. Teams of farmers, teachers, and lawyers were trained to recognize the signs and symptoms of Ebola and were instructed to present unannounced at health centers to examine the records of recently discharged and presently interned patients. If these non-medical professionals found a patient's records to include even one symptom of Ebola—say, a 5-year old child who presented with a fever and low appetite and tested positive for malaria; or a woman who was 8-weeks pregnant who presented with bleeding and was found to have a miscarriage—they activated an Ebola alert, which, if verified, led to the deportation of the patient to the Ebola system.

While the Response's triage system had remained outside of the existing health system, the surveillance teams entered the health centers and hospitals and removed patients from within their walls. As non-medical personnel forcefully entered private health structures and overrode the clinical judgment of the healthcare providers who worked there, they created a clear hierarchy between the surveillance teams (largely comprised of non-medical staff, often from outside of the community) and local healthcare providers who had long been working to improve the health of their communities. This greatly offended healthcare providers in these centers; it also encouraged fugitive practices such as the hiding of patients or hospital records from the surveillance teams. <sup>175</sup> Instead of training local healthcare workers to recognize Ebola, which would have improved outcomes for this epidemic and those in the future, the Response imposed an active surveillance arm onto the existing healthcare structures, thereby undermining local trust in the medical system as a whole.



### **Transit Centers**

Once they triggered an Ebola alert, whether in the community or at a health facility, those who displayed symptoms of Ebola were brought to transit centers to be tested. In general, patients remained in transit centers for three days, awaiting two negative Ebola tests<sup>176</sup> Some basic medications were provided; however, diagnostic capability was low in these centers, and pharmacies limited. In addition, these facilities were often overcrowded and under-resourced, with some patients waiting a full day to get a bed, and many patients assigned to one healthcare provider. As a result of the overcrowding and the limited diagnostic and treatment capacity, in our ethnographic work in these transit centers, we observed poor health outcomes in these centers. We also recorded many stories of those who presented critically ill with a non-Ebola illness—for example peritonitis, miscarriage, or severe malaria—who got caught in these under-resourced transit centers and died as they waited for the results of their Ebola tests.

In the end, removing people from their communities and healthcare centers for testing in transit centers caused significant fear. It also had poor outcomes. In addition to the deaths recorded within the Ebola system due to its lack of capacity, there was still a high rate of Ebola transmission within health centers: 16 percent of Ebola infections happened within health centers during this epidemic. MSF has proven the effectiveness of integrated triage and testing systems. What is still lacking is the political will to invest in the existing health structures to prepare them to recognize, isolate, and diagnose Ebola, as they recognize, isolate, and diagnose other infectious illnesses.

### **Ebola Treatment Centers**

The final piece of the parallel system was the Ebola Treatment Centers (ETCs) themselves. While some portion of ETCs did serve as transit centers, boarding patients while they awaited their Ebola tests, the majority of the activity in ETCs was dedicated to the treatment of patients who had tested positive for Ebola. As noted above, significant clinical advances in Ebola care were made during this epidemic, including the testing of treatment molecules, the preliminary results of which were positive. The institution of treatment protocols that emphasized aggressive resuscitation and close electrolyte management also contributed significantly to improved outcomes. While overall mortality during the epidemic remained high due to the prevalence of community deaths—people who died of Ebola in their homes, without having come to ETCs—the overall mortality of those who were treated at ETCs was lower, 50 percent, and even lower amongst the group that came to ETCs early in their disease course—34 percent.<sup>178</sup>

While ETCs saved lives, they also inspired fear.<sup>179</sup> In North Kivu, the population called ETCs "a hammer," "the final act," and "a death corridor [un mouroir]," indicating how closely ETCs were tied with death in the popular imagination. Certainly, the public health messages that had circulated early in the epidemic—"Ebola kills," "There is no cure for Ebola"—had done significant damage. As had been done in other epidemics, the Response made efforts to render the care delivered in the ETCs more transparent: visitors were encouraged; community tours



of the ETCs were provided; and ALIMA's clear, plastic isolation units were used. And still, in our interviews, people asserted that it was not just a matter of clear plastic sheeting, of being able to see; rather, where trust has been eroded by years of neglect and war, geography matters. Sixty-one percent of people in our household survey stated that they would prefer to go to the center closest to them (as opposed to a hospital or ETC) to be treated if they were sick with Ebola-like symptoms.

In West Africa, a parallel Ebola system was created, in part, because of how overwhelmed the national health systems were. Where so many facilities had shuttered due to infected staff and a broken supply chain, a parallel system needed to be erected, at least temporarily, to control the epidemic.<sup>181</sup> The situation in Congo was radically different. Even the Mangina Referral Center, the initial epicenter of the disease, the center most affected by the disease, closed temporarily only after the ETC had been built and other centers had been prepared to receive additional volume of patients. In Congo, largely due to the administration of rVSV-ZEBOV vaccine to healthcare workers, most healthcare workers were protected from infection, and health centers remained open.<sup>182</sup> Additionally, due to the implementation of free health for several months at the beginning of the epidemic, <sup>183</sup> the healthcare system actually saw increased volume during the epidemic, in contrast to the massive decreases in volume seen in West Africa.<sup>184</sup> Overall, the Congolese health system has largely remained standing during the tenth epidemic.<sup>185</sup> And still, a parallel system was implemented—and continued, even after feedback of its detrimental effects.

Both in the community and in the clinical context, the Response did not recognize the existing public health practices and infrastructure and instead created a parallel Ebola system to fight Ebola. Whether this was mere oversight or a strategic refusal to engage with existing systems, we argue that it partakes in the same racist logic that has historically denied recognition to Black and African systems of knowledge and practice. As in the colonial period, where the biomedical systems was designed to replace traditional systems of medicine, the Response created a parallel Ebola system to replace, if temporarily, existing Congolese systems of infection control. In so doing, the Response privileged the containment of Ebola over the autonomy and overall well-being of the Congolese population living in North Kivu. It also undermined its own containment measures and added to early death in non-Ebola cases.

Importantly, while the parallel system was mostly dismantled at the end of the epidemic, its effects will likely continue to be felt for some time. While it still functioned, the parallel system drew trained Congolese heal-thcare providers away from their jobs in public health structures, thereby contributing to the deterioration of care in the already-understaffed and undertrained non-Ebola health system. We do not yet know how many healthcare providers who transitioned to the Response during Ebola will return to their posts once Ebola is declared over. Neither do we yet know how the withdrawal of Ebola funding streams and personnel will affect healthcare—and the stability of society generally—in the Grand Nord.

One thing that has become very clear in our research, however, is that the construction of a parallel Ebola system—and all of the rifts between population and health system that the parallel system caused—worsened the already crippling load of structural violence in North Kivu. And because violence begets violence, the ghosts it leaves behind will likely reverberate through the region for some time.



# Conclusion

The successful management of epidemics requires functional health systems. In the wake of the West African Ebola epidemic, a discussion emerged about the components of resilient healthcare systems. One of the first pillars of resilient healthcare systems is quality healthcare during noncritical times. But what is quality care? In the DRC, quality care would mean motivated and educated community health workers; a reliable supply chain for vaccines and essential medications; robust triage, isolation, and critical care areas in every hospital; a healthcare administration that works to reduce user fees and increase access; and a public health system that fights for security in all its forms—access to water, food security, physical safety—for its population.

Certainly, the construction of a health system equipped to provide quality care is a significant investment. So, too, is an epidemic response. Nearly \$1 billion was spent on this epidemic response; \$14 billion was spent in West Africa. And the frequency of these epidemics is increasing. This epidemic was declared several days after the ninth epidemic had ended; an eleventh epidemic had already emerged before this epidemic could even be declared over. In addition to Ebola, the region is also battling a measles epidemic, which has already killed almost three times the number of people that died in the tenth Ebola epidemic, and the COVID-19 pandemic, which poses great danger to a country with minimal capacity to contain respiratory viruses. As one WHO staff member put it after the diagnosis of the first COVID-19 cases in the country, "We can't wait for one epidemic to end to build the system. It is clear that the epidemics will continue—we must build now or else we'll never be able to stop people from dying." While we were talking specifically about the DRC, the same holds for many countries around the globe. Previously controlled diseases such as polio and measles have seen a resurgence around the world. The increasing frequency with which new epidemics have arisen—SARS, MERS, and COVID-19 within two decades—demonstrates the urgency for reinvesting in healthcare globally.

The "lessons learned" from this epidemic have already begun to be applied to the COVID-19 response. <sup>191</sup> Yet great caution must be taken with this approach. As in the West African case, the ethical underpinning of the failures of humanitarian response must be recognized. <sup>192</sup> Instead of merely things-we-could-do-better-next-time, these lessons indicate the need for "a sea change in the values that undergird our attitude to global public health emergency preparedness and response." <sup>193</sup> In the end, rebuilding the Congolese health system will be the most effective way to control epidemics. It is also the ethical thing to do; far more than infectious disease drives Congo's early mortality rate. Most importantly, building the Congolese health system is the only way to ensure that another parallel system will not arise in the future, whether in response to an Ebola epidemic, in an effort to address high rates of TB or HIV, or for any other reason. Overall, setting up a parallel system is based on a flawed premise, implying that it would be too difficult, expensive, or slow to set up resilient heal-thcare systems. This approach only compounds the structural violence of the Congolese healthcare system.



During its last two meetings as a group, CRG's ethnographic team worked together to imagine a version of a response that took into account the lessons learned from our research. Because of the team's diversity—physicians and activists, conflict researchers and parents—healthy discussion and debate ensued. We drew diagram after diagram trying to formulate a model for epidemic management that was based in the community and existing health structures and required little national or international assistance. After two days, we reviewed the model that we had created.

In this new model, all activities were based in the state-run public health system. While lacking in many ways, the system is well-structured and rich in human resources. To respond appropriately to an epidemic, those working in the existing system—relais communautaires, individual healthcare providers, public health authorities—would need only specific training to be able to serve as an integrated Response, which is motivated by high a commitment to the community that they have always served. It is true that many people would need to be trained quickly. The Congolese health system is decentralized by design. Nuanced, specific information about Ebola could be disseminated quickly, from the central offices in each health zone, to each state-run structure in the zone, and on to networks of traditional healers and informal clinics operating in the area. Until more Congolese can be trained in epidemiology and epidemic management, a handful of expatriate epidemic management experts would be needed to guide the development of training materials, analyze the epidemiology of the epidemic, and weigh in on the necessity of increasing epidemic control measures (such as handwashing stations or limitations to movement). However, the footprint of this staff could be kept very small by ensuring that they remained in an advisory role only. And while the treatment of Ebola-positive patients remains guite specialized and technical, humanitarian organizations with significant experience in disease management—namely, MSF and ALIMA—would still be needed to run Ebola treatment centers. All other sensitization, contact tracing, burial, vaccination, and triage responsibilities could be organized at the level of the local, formal health structures, with significant involvement of the community. In the end, it is the community that would lead, not any international organization that "goes where no one else will go and stays long after everyone else has left," as WHO staff claimed during this Response. 194

Looking at the new Ebola Response we had created, which required so little international investment or personnel, one team member shook his head. "Ebola is a vignette, a clue that reveals the violence which Congolese suffer every day [Ebola est une vignette. Un indice qui montre la violence que les Congolais subissent chaque jour]," he offered. "They told us that we could not do it on our own, but we have just drawn a model that puts [local] Congolese action at the center." He paused before continuing, "It is possible."

Prior to this epidemic, Ebola epidemics in Congo were effectively controlled within months of their detection, with relatively few international resources or personnel. Despite—or perhaps because of—the massive international investment in this Response, and the fear and militarization that have resulted, the epidemic has taken nearly two years to control, and has killed more than 2200 people. Indeed, this epidemic occurred near an urban area, in a conflict zone; however, importantly, the epidemic only propagated significantly in urban areas after the Response became more militarized, The pre-existing conflict, between the government forces and armed groups, never directly affected the Response.



The haste to bypass the existing health system by creating a parallel one ended up generating resistance and violence. The only way to break the cycle is to eliminate the need for massive, international epidemic responses in the first place. At a strategic meeting for the Response in October 2019, the Minister of Health pleaded to all present, "Ebola is temporary; please invest in our health system, for the future." We agree.

# Methodology and Baseline Data

In its study of the parallel Ebola system in North Kivu, <sup>195</sup> this project used a combination of ethnography, a household survey, and retrospective hospital data. To assess areas most affected by Ebola, the geographical area of study was defined to be the six health zones in North Kivu that recorded over 100 cases of Ebola: Beni, Butembo, Katwa, Vuhovi, Kalunguta, and Mabalako. Between January and March 2020, our researchers studied the myriad practices that Congolese developed to care for Ebola outside of the official Ebola system in these areas. Additionally, they spent time with Response surveillance teams, in transit centers, in Ebola Treatment Centers (ETCs), and in other formal and informal health structures in the area. <sup>196</sup> In the household study, four health zones in North Kivu that were not significantly affected by Ebola or the Response were included as controls. <sup>197</sup> A total of 3631 households were queried about the impact of Ebola and the Response on the community. In addition, interviews were conducted and retrospective hospital data was collected at 56 health structures and six central health zones. Finally, more than two hundred presentations, publications, and reports—including the 57 population-level qualitative and quantitative studies conducted by the Response itself<sup>198</sup>—were reviewed in the course of the study and preparation of this report. Further methodological data is available in Appendix 1. Baseline data on health zones included in this study is included in Table 1.



### **Endnotes**

- 1. Jorge E. Pinzon et al., "Trigger Events: Enviroclimatic Coupling of Ebola Hemorrhagic Fever Outbreaks," *The American Journal of Tropical Medicine and Hygiene 71*, no. 5 (2004): 664–74, https://doi.org/10.4269/ajtmh.2004.71.664
- Eugene T. Richardson et al., "The Ebola Suspect's Dilemma," The Lancet Global Health 5, no. 3 (March 1, 2017): e254–56, <a href="https://doi.org/10.1016/S2214-109X(17)30041-4">https://doi.org/10.1016/S2214-109X(17)30041-4</a> argue that, in the West African epidemic, a person presenting with signs of Ebola actually had a greater chance of dying from Ebola if he pursued care in health centers than if he remained at home.
- 3. Brolin Ribacke et al., "Effects of the West Africa Ebola Virus Disease on Health-Care Utilization A Systematic Review," Frontiers in Public Health 4 (2016), https://doi.org/10.3389/fpubh.2016.00222
- 4. Håkon Bolkan et al., "Ebola and Indirect Effects on Health Service Function in Sierra Leone," PLoS Currents, 2014, https://doi.org/10.1371/currents.outbreaks.0307d588df619f9c9447f8ead5b72b2d; Håkon Bolkan et al., "Admissions and Surgery as Indicators of Hospital Functions in Sierra Leone during the West-African Ebola Outbreak," BMC Health Services Research 18, no. 1 (December 2018): 846, https://doi.org/10.1186/s12913-018-3666-9
- 5. The WHO defines a "Public Health Emergency of International Concern (PHEIC)" to be "a situation that is serious, unusual or unexpected; carries implications for public health beyond the affected State's national border; and may require immediate international action" WHO, "International Health Regulations" (WHO, 2005 2008), 9, <a href="https://apps.who.int/iris/bitstream/handle/10665/43883/9789241580410\_eng.pdf?sequence=1">https://apps.who.int/iris/bitstream/handle/10665/43883/9789241580410\_eng.pdf?sequence=1</a>. The declaration of a PHEIC marks the transformation of a public health issue into a security threat. At the same time, it calls into question the knowledge of conventional disease control. By definition, a PHEIC is exceptional, and therefore a challenge to the kinds of expert knowledge that inform "ordinary" responses to disease Ann H. Kelly, "Ebola Vaccines, Evidentiary Charisma and the Rise of Global Health Emergency Research," Economy and Society 47, no. 1 (January 2, 2018): 135–61, <a href="https://doi.org/10.1080/03085147.2018.1448557">https://doi.org/10.1080/03085147.2018/148557</a>
- 6. Terrence Q. Lo et al., "Ebola: Anatomy of an Epidemic," *Annual Review of Medicine* 68 (2017): 359–70, <a href="https://doi.org/10.1146/annurev-med-052915-015604">https://doi.org/10.1146/annurev-med-052915-015604</a>.; Ismail O.D. Rashid and Semiha Abdulmelik, eds., *Understanding West Africa's Ebola Epidemic: Towards a Political Economy. Security and Society in Africa* (London: Zed Books, 2017).
- 7. Alyssa S. Parpia et al., "Effects of Response to 2014–2015 Ebola Outbreak on Deaths from Malaria, HIV/AIDS, and Tuberculosis, West Africa," Emerging Infectious Diseases 22, no. 3 (March 2016): 433–41, https://doi.org/10.3201/eid2203.150977
- 8. Michael Edelstein, Philip Angelides, and David L. Heymann, "Ebola: The Challenging Road to Recovery," *The Lancet* 385, no. 9984 (June 6, 2015): 2234–35, https://doi.org/10.1016/S0140-6736(15)60203-3
- Yves Lévy et al., "Prevention of Ebola Virus Disease through Vaccination: Where We Are in 2018," The Lancet 392, no. 10149 (2018): 787–90, <a href="https://doi.org/10.1016/S0140-6736(18)31710-0">https://doi.org/10.1016/S0140-6736(18)31710-0</a>; Amanda Rojek, Peter Horby, and Jake Dunning, "Insights from Clinical Research Completed during the West Africa Ebola Virus Disease Epidemic," The Lancet Infectious Diseases 17, no. 9 (2017): 280–92, <a href="https://doi.org/10.1016/S1473-3099(17)30234-7">https://doi.org/10.1016/S1473-3099(17)30234-7</a>
- 10. Interviews with WHO and MSF staff present near the beginning of the epidemic.
- 11. In this report, we use the term "Response" to describe the coalition of Congolese government officials, UN agencies, and humanitarian organizations that formed to fight the tenth Ebola epidemic in Congo. For most of the epidemic, this coalition self-identified and was identified by the Congolese population as "la Riposte," a French term denoting an often militarized counterattack to an initial attack (in this case, Ebola). However, in response to feedback that the militarized word "Riposte" was negatively affecting community relations, the Riposte changed its name to "la Réponse"—the Response—in early 2020. While local community members often still use the name "Riposte," we use the official term, "Response," in this report.
- 12. A few months after the epidemic was declared, the Response developed a social science research arm, initially small, which eventually developed into the *Cellule d'Analyse en Science Sociale* (CASS). In addition to presenting their results at Response and stakeholder meetings, CASS shared their data openly on a Google drive; review of this research as well as conversations with CASS staff has significantly shaped this report. For a summary on CASS's research, see CASS, "Social Science Support for COVID-19: Lessons Learned Brief 1. What Social Sciences Researchers Working in Humanitarian Contexts (Sub-Saharan Africa) Should Be Asking in COVID-19 and Why" (UNICEF, May 22, 2020), <a href="https://www.unicef.org/drcongo/media/4111/file/CASS-Brief1-Questions.pdf">https://www.unicef.org/drcongo/media/4111/file/CASS-Brief1-Questions.pdf</a>; CASS, "Social Science Support for COVID-19: Lessons Learned Brief 2. Gender Inclusiveness in COVID-19 Humanitarian Response Operations, Evidence from Social Sciences Outbreak Research" (UNICEF, May 22, 2020), <a href="https://www.unicef.org/drcongo/media/4121/file/CASS-Brief2-Gender.pdf">https://www.unicef.org/drcongo/media/4121/file/CASS-Brief2-Gender.pdf</a>; CASS, "So-



cial Science Support for COVID-19: Lessons Learned Brief 3. Humanitarian Programme Recommendations for COVID-19 Based on Social Sciences Evidence from the DRC Ebola Outbreak Response" (UNICEF, May 22, 2020), <a href="https://www.unicef.org/drcongo/media/4131/file/CASS-Brief3-recommendations.pdf">https://www.unicef.org/drcongo/media/4131/file/CASS-Brief3-recommendations.pdf</a>; CASS, "Social Science Support for COVID-19: Lessons Learned Brief 4. Social Sciences Evidence on Barriers to Healthcare Seeking during the DRC Ebola Outbreak" (UNICEF, May 22, 2020), <a href="https://www.unicef.org/drcongo/media/4141/file/CASS-Brief4-barriers.pdf">https://www.unicef.org/drcongo/media/4141/file/CASS-Brief4-barriers.pdf</a>; CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas.," April 2020, <a href="https://docs.google.com/document/d/14UIaFEAjcsdQNefrikniKb3iU5YGoUr2t4hJSrunhXI/edit?usp=drive\_web&ouid=101244407477129239000&usp=embed\_facebook;">https://docs.google.com/document/d/14UIaFEAjcsdQNefrikniKb3iU5YGoUr2t4hJSrunhXI/edit?usp=drive\_web&ouid=101244407477129239000&usp=embed\_facebook;</a>; Linda Meta Mobula et al., "Recommendations for the COVID-19 Response at the National Level Based on Lessons Learned from the Ebola Virus Disease Outbreak in the Democratic Republic of the Congo, *The American Journal of Tropical Medicine and Hygiene*, May 19, 2020, <a href="https://docs.google.com/document/d/16.4269/ajtmh.20-0256">https://docs.google.com/document/d/16.4269/ajtmh.20-0256</a>

- 13. This is the first of a set of three reports funded by the European Union and published by the Congo Research Group on the tenth Ebola epidemic in Congo and its political, social, economic, and security-related aspects. Due to security concerns, researchers at Centers for Disease Control (CDC), one of the largest contributors to epidemic management and research in the West African epidemic, were largely prohibited from leaving Goma—meaning that all CDC research was done remotely during this epidemic, with experts conducting analyses and writing briefs without ever having seen the context about which they were writing. The same travel restrictions applied to many academics—or at least their grant money—who had previously contributed to the West African epidemic.
- 14. In this report, we do not analyze gender separately. This has already been done, and done well, by several researchers. See, for example, CASS, "Social Science Support for COVID-19: Lessons Learned Brief 2. Gender Inclusiveness in COVID-19 Humanitarian Response Operations, Evidence from Social Sciences Outbreak Research," *UNICEF*, 2020, <a href="https://www.unicef.org/drcongo/media/4121/file/CASS-Brief2-Gender.pdf">https://www.unicef.org/drcongo/media/4121/file/CASS-Brief2-Gender.pdf</a>; Nidhi Kapur, "Gender Analysis: Prevention and Response to Ebola Virus Disease in the Democratic Republic of Congo" (CARE, January 2020), <a href="https://www.care-international.org/files/files/Ebola\_Gender\_Analysis\_English\_v2.pdf">https://www.care-international.org/files/files/Ebola\_Gender\_Analysis\_English\_v2.pdf</a>; IRC, "Not All That Bleeds Is Ebola: How Has the DRC Ebola Outbreak Impacted Sexual and Reproductive Health in North Kivu?," February 2020, <a href="https://www.rescue.org/sites/default/files/document/4416/srhebolareport1172020.pdf">https://www.rescue.org/sites/default/files/document/4416/srhebolareport1172020.pdf</a>; "Guidelines for the Management of Pregnant and Breastfeeding Women in the Context of Ebola Virus Disease" (WHO, February 2020), <a href="https://apps.who.int/iris/rest/bitstreams/1268115/retrieve">https://apps.who.int/iris/rest/bitstreams/1268115/retrieve</a>
- 15. Melissa Leach brings the concept of structural violence to an analysis of the West African Ebola epidemic, which she describes as "a combination of institutions have contributed to longer-term inequalities, unsustainabilities and insecurities." Melissa Leach, "The Ebola Crisis and Post-2015 Development: Ebola and Post-2015 Development," *Journal of International Development* 27, no. 6 (August 2015): 816–34, <a href="https://doi.org/10.1002/jid.3112">https://doi.org/10.1002/jid.3112</a>. See also Annie Wilkinson and Melissa Leach, "Briefing: Ebola–Myths, Realities, and Structural Violence," *African Affairs* 114, no. 454 (January 1, 2015): 136–48, <a href="https://doi.org/10.1093/afraf/adu080">https://doi.org/10.1093/afraf/adu080</a>
- 16. Here, we draw from Nancy Scheper-Hughes and Philippe Bourgois, "Introduction: Making Sense of Violence," in Violence in War and Peace: An Anthology, ed. Nancy Scheper-Hughes and Philippe Bourgois, Nachdr, Blackwell Readers in Anthropology 5 (Malden, Mass.: Blackwell Publ, 2007), 1–34. Both authors have written extensively on violence; however, this particular chapter specifically explores the idea of a violence continuum.
- 17. Since 1976, Professor Muyembe has played a key role in Ebola management in Congo as well as in the science behind Ebola vaccines, clinical management, and therapeutics. Muyembe's research has led directly to the development of the rVSV-ZEBOV vaccination and mAb114 treatment molecule. During this Response, Muyembe served as the coordinator (from July 2019 on), and the co-PI on several of the important clinical trials.
- 18. Kathleen A. Alexander, Claire E. Sanderson, Madav Marathe, Bryan L. Lewis, Caitlin M. Rivers, Jeffrey Shaman, and John M. Drake, "What Factors Might Have Led to the Emergence of Ebola in West Africa?," *PLoS Neglected Tropical Diseases* 9, no. 6 (2015), <a href="https://doi.org/10.1371/journal.pntd.0003652">https://doi.org/10.1371/journal.pntd.0003652</a>
- 19. See Jasbir K. Puar, *Terrorist Assemblages: Homonationalism in Queer Times*, Second edition, Next Wave (Durham: Duke University Press, 2017) for a discussion of the creation of the category of a terrorist group.
- 20. Andrew Lakoff, Unprepared: Global Health in a Time of Emergency (Oakland, California: University of California Press, 2017).
- 21. Matthew Herder, Janice E. Graham, and Richard Gold, "From Discovery to Delivery: Public Sector Development of the RVSV-ZEBOV Ebola Vaccine," *Journal of Law and the Biosciences*, January Isz019 (2020), <a href="https://doi.org/10.1093/jlb/Isz019">https://doi.org/10.1093/jlb/Isz019</a>
- 22. Melissa Leach and Barry S. Hewlett, "Haemorrhagic Fevers: Narratives, Politics and Pathways," in *Epidemics: Science, Governance and Social Justice*, ed. Sarah Dry and Melissa Leach (London; Washington, DC: Earthscan, 2010), 43–69; Leach, "The Ebola Crisis and Post-2015 Development"; Steven Pokornowski, "Insecure Lives: Zombies, Global Health, and the Totalitarianism of Generalization," *Literature and Medicine* 31, no. 2 (2013): 216–34, <a href="https://doi.org/10.1353/lm.2013.0017">https://doi.org/10.1353/lm.2013.0017</a>; Veronica Gomez-Temesio, "Outliving Death: Ebola, Zombies, and the Politics of Saving Lives," *American Anthropologist* 120, no. 4 (2018): 738–51, <a href="https://doi.org/10.1111/aman.13126">https://doi.org/10.1111/aman.13126</a>. See also Hannah Brown and Ann H. Kelly, "Material Proximities and Hotspots: Toward an Anthropology of Viral Hemorrhagic Fevers: Material Proximities and Hotspots," *Medical Anthropology Quarterly* 28, no. 2 (2014): 280–303, <a href="https://doi.org/10.1111/maq.12092">https://doi.org/10.1111/maq.12092</a> for a compelling



discussion on the problem of the outbreak narrative.

- 23. Nicholas B. King, "Security, Disease, Commerce: Ideologies of Postcolonial Global Health," *Social Studies of Science* 32, no. 5–6 (December 2002): 763–89, https://doi.org/10.1177/030631270203200507
- 24. Lakoff, Unprepared.
- 25. Edelstein, Angelides, and Heymann, "Ebola"; Lakoff, Unprepared.
- 26. United Nations Security Council, S/RES/2177(2014) E S/RES/2177(2014) § (2014), https://undocs.org/S/RES/2177(2014)
- 27. Alex de Waal, "Militarizing Global Health," Boston Review. November 11 (2014), <a href="http://bostonreview.net/world/alex-de-waal-militarizing-global-health-ebola">http://bostonreview.net/world/alex-de-waal-militarizing-global-health-ebola</a>
- 28. Adia Benton, "Whose Security? Militarization and Securitization During West Africa's Ebola Outbreak," in *The Politics of Fear: Médecins sans Frontières and the West African Ebola Epidemic*, ed. Michiel Hofman and Sokhieng Au (New York, NY, United States of America: Oxford University Press, 2017), 25–50.
- 29. Tracing the privatization of the biosecurity apparatus, King, "Security, Disease, Commerce" argues that the nexus includes public health, security, and commerce. While not discussed here, the rise of biosecurity led to the development of a biosecurity industry has resulted in significant profits for some. See also Andrew Lakoff, "The Generic Biothreat, or How We Became Unprepared," *Cultural Anthropology* 23, no. 3 (2008): 399–428, https://doi.org/10.1111/j.1548-1360.2008.00013.x
- 30. Benton, "Whose Security? Militarization and Securitization During West Africa's Ebola Outbreak" writes, "the conscious coupling of military and humanitarian approaches demands that we ask whose lives are amenable for protection and rescue through the threat of force, which people may demand obedience from Ebola-affected communities, and on whose terms these demands can be made. Ultimately, this helps us to understand whose security is prioritized and from what dangers or threats they are being protected" (31). The phenomenon of "selective caring" has also been discussed in terms of social triage in Vinh-Kim Nguyen, *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*, Body, Commodity, Text (Durham, NC: Duke University Press, 2010); Adia Benton, "Ebola at a Distance: A Pathographic Account of Anthropology's Relevance," *Anthropological Quarterly* 90, no. 2 (2017): 495–524, https://doi.org/10.1353/anq.2017.0028
- 31. Pierre Nouvellet et al., "The Role of Rapid Diagnostics in Managing Ebola Epidemics," *Nature* 528, no. 7580 (2015): 109–16, <a href="https://doi.org/10.1038/nature16041">https://doi.org/10.1038/nature16041</a>. Also see Lieselotte Cnops et al., "Where Are the Ebola Diagnostics from Last Time?," *Nature* 565, no. 7740 (January 2019): 419–21, <a href="https://doi.org/10.1038/d41586-019-00212-y">https://doi.org/10.1038/d41586-019-00212-y</a> for a discussion about why the majority of these tests were not available on the market, for use in this epidemic.
- 32. Rojek, Horby, and Dunning, "Insights from Clinical Research Completed during the West Africa Ebola Virus Disease Epidemic."
- 33. Tini Garske et al., "Heterogeneities in the Case Fatality Ratio in the West African Ebola Outbreak 2013–2016," *Philosophical Transactions of the Royal Society B: Biological Sciences* 372 (2017): 20160308, https://doi.org/10.1098/rstb.2016.0308
- 34. Timothy M. Uyeki et al., "Clinical Management of Ebola Virus Disease in the United States and Europe," New England Journal of Medicine 374, no. 7 (2016): 636–46, <a href="https://doi.org/10.1056/NEJMoa1504874">https://doi.org/10.1056/NEJMoa1504874</a>. Shelley-Egan and Dratwa have highlighted the moral failure of evacuating European healthcare workers who developed Ebola in caring for patients while leaving their Ebola-positive West African counterparts. They call this "selective caring." Clare Shelley-Egan and Jim Dratwa, "Marginalisation, Ebola and Health for All: From Outbreak to Lessons Learned," International Journal of Environmental Research and Public Health 16, no. 17 (2019): 3023, <a href="https://doi.org/10.3390/ijerph16173023">https://doi.org/10.3390/ijerph16173023</a>
- 35. Vinh-Kim Nguyen, "Ebola: How We Became Unprepared, and What Might Come Next," *Fieldsights Hot Spots, Cultural Anthropology Online* (blog), October 7, 2014, <a href="https://culanth.org/fieldsights/ebola-how-we-became-unprepared-and-what-might-come-next">https://culanth.org/fieldsights/ebola-how-we-became-unprepared-and-what-might-come-next</a>
- 36. Nancy Rose Hunt, "'Le Bebe En Brousse': European Women, African Birth Spacing and Colonial Intervention in Breast Feeding in the Belgian Congo," The International Journal of African Historical Studies 21, no. 3 (1988): 401, https://doi.org/10.2307/219448; Jean Comaroff, "The Diseased Heart of Africa: Medicine, Colonialism, and the Black Body," in Knowledge, Power, and Practice: The Anthropology of Medicine and Everyday Life, ed. Shirley Lindenbaum and Margaret M. Lock, Comparative Studies of Health Systems and Medical Care (Berkeley: University of California Press, 1993), 305–29; Nancy Rose Hunt, A Nervous State: Violence, Remedies, and Reverie in Colonial Congo (Durham, NC: Duke University Press, 2016).



- 37. A similar argument could be made about keeping a healthy workforce for mineral wealth extraction. See Nancy Rose Hunt, "An Acoustic Register, Tenacious Images, and Congolese Scenes of Rape and Repetition," *Cultural Anthropology* 23, no. 2 (May 1, 2008): 220–53, <a href="https://doi.org/10.1111/j.1548-1360.2008.00008.x">https://doi.org/10.1111/j.1548-1360.2008.00008.x</a>; Hunt, *A Nervous State: Violence, Remedies, and Reverie in Colonial Congo.*
- 38. Hunt, "An Acoustic Register, Tenacious Images, and Congolese Scenes of Rape and Repetition"; Hunt, A Nervous State: Violence, Remedies, and Reverie in Colonial Congo.
- 39. Obviously, this preference is uneven and multifactorial. In our conversations about traditional medicine versus biomedicine, people mentioned the following justifications: the side effects of biomedicine could be more severe than traditional medicine; traditional medicine felt "natural" because it relied on plants instead of factories; traditional healers spoke Swahili instead of the French that was sometimes spoken by biomedical providers; and traditional healers were neighbors as opposed to "strangers" in the formal health centers.
- 40. Maryinez Lyons, "Public Health in Colonial Africa: The Belgian Congo," in *The History of Public Health and the Modern State*, ed. Dorothy Porter (Rodopi, 1994).
- 41. Aembe Bwimana, "Heath Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," *Health Policy and Planning* 32, no. 10 (December 1, 2017): 1476–83, <a href="https://doi.org/10.1093/heapol/czx095">https://doi.org/10.1093/heapol/czx095</a>
- 42. Ron Waldman, "Health in Fragile States, Country Case Study: Democratic Republic of the Congo." (Arlington, Virginia, USA, 2006); Bwimana, "Heath Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," December 1, 2017; République Democratique du Congo Ministère de la Santé, "Stratégie de Renforcement du Système de Santé," June 2006, <a href="https://planificationfamiliale-rdc.net/docs/2\_StrategieDeRenforcementDuSystemeDeSante\_SRSS\_Juin2006.pdf">https://planificationfamiliale-rdc.net/docs/2\_StrategieDeRenforcementDuSystemeDeSante\_SRSS\_Juin2006.pdf</a>; Ngoyi K. Z. Bukonda et al., "Health Care Entrepreneurship in the Democratic Republic of the Congo: An Exploratory Study," *Journal of African Business* 13, no. 2 (May 2012): 87–100, <a href="https://doi.org/10.1080/15228916.2012.693433">https://doi.org/10.1080/15228916.2012.693433</a>
- 43. Here, Mobutu was clear that these community healthcare workers should be unpaid so as to ground them in their own community, to ensure that the attention to a community's health came from within, as opposed to be being imposed from the outside. See République Democratique du Congo Ministère de la Santé, "Stratégie de Renforcement du Système de Santé." See also Denis Porignon et al., "How Robust Are District Health Systems? Coping with Crisis and Disasters in Rutshuru, Democratic Republic of Congo: How Robust Are District Health Systems?," *Tropical Medicine & International Health* 3, no. 7 (1998): 559–65, https://doi.org/10.1046/j.1365-3156.1998.00263.x
- 44. Hunt, "Le Bebe En Brousse"; Waldman, "Health in Fragile States, Country Case Study: Democratic Republic of the Congo"; Theodore Trefon, ed., Reinventing Order in Congo: How People Respond to State Failure in Kinshasa (London; New York: Kampala, Uganda: Zed Books, ; Fountain Publishers, 2004).
- 45. Bwimana, "Heath Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," December 1, 2017; Maria Paola Bertone, Grégoire Lurton, and Paulin Beya Mutombo, "Investigating the Remuneration of Health Workers in the DR Congo: Implications for the Health Workforce and the Health System in a Fragile Setting," Health Policy and Planning 31, no. 9 (2016): 1143–51, https://doi.org/10.1093/heapol/czv131; Bertone, Lurton, and Mutombo; S. Fox et al., "Paying Health Workers for Performance in a Fragmented, Fragile State: Reflections from Katanga Province, Democratic Republic of Congo," Health Policy and Planning 29, no. 1 (2014): 96–105, https://doi.org/10.1093/heapol/czs138
- 46. Crawford Young and Thomas Turner, *The Rise and Decline of the Zairian State* (Madison, Wis: University of Wisconsin Press, 1985); Aembe Bwimana, "Heath Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," *Health Policy and Planning* 32, no. 10 (2017): 1476–83, <a href="https://doi.org/10.1093/heapol/czx095">https://doi.org/10.1093/heapol/czx095</a>
- 47. For more on the role of the church in the Congolese health system, see Laura Seay, "Effective Responses: Protestants, Catholics and the Provision of Health Care in the Post-War Kivus," Review of African Political Economy 40, no. 135 (2013): 83–97, https://doi.org/10.1080/03 056244.2012.761601; Matthieu Muhemu Sabao Sitone, "Naissance et croissance d'une Eglise locale: 1896/97 1996 Le cas du diocèse de Butembo-Beni au Congo-Kinshasa (RDC)" (Religions, sociétés et acculturation (RESEA) LARHRA, UMR 5190, 2006), http://journals.openedition.org/chretienssocietes/2089. See also Waldman, "Health in Fragile States, Country Case Study: Democratic Republic of the Congo."
- 48. Bwimana, "Heath Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," 2017, 1479.
- 49. Dennis Dijkzeul, "Healing Governance? Four Health NGOs in War-Torn Eastern Congo," *Journal of International Affairs* 57, no. 1 (Fall 2003): 183–89; Fox et al., "Paying Health Workers for Performance in a Fragmented, Fragile State: Reflections from Katanga Province, Democratic Republic of Congo."
- 50. Porignon et al., "How Robust Are District Health Systems? Coping with Crisis and Disasters in Rutshuru, Democratic Republic of Congo: How Robust Are District Health Systems?"



- 51. World Bank Group (2018). "The Role of the Private Sector in Improving the Performance of the Health System in the Democratic Republic of the Congo" <a href="http://documents1.worldbank.org/curated/en/487571539958646859/pdf/131045-REVISED-23-1-2019-10-49-58-WB-DRCPSAEnglishWEB.pdf">http://documents1.worldbank.org/curated/en/487571539958646859/pdf/131045-REVISED-23-1-2019-10-49-58-WB-DRCPSAEnglishWEB.pdf</a>, p.48.
- 52. Some health indicators have improved: life expectancy in the DRC has gone from 49.04 years in 1996 to 60.37 years in 2018. See <a href="https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=CD">https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=CD</a>. But this change is arguably due to disease-specific donor-funded programs rather than increased state expenditures in the health sector. République Democratique du Congo Ministère de la Santé, "Stratégie de Renforcement du Système de Santé"; Bertone, Lurton, and Mutombo, "Investigating the Remuneration of Health Workers in the DR Congo: Implications for the Health Workforce and the Health System in a Fragile Setting"; Bwimana, "Heath Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," 2017.
- 53. For more on African postcolonial state extraction, see (Young 2012; Mbembe 2001; Ferguson 2006; Kisangani and Pickering 2014).
- 54. Benjamin Coghlan et al., "Update on Mortality in the Democratic Republic of Congo: Results From a Third Nationwide Survey," *Disaster Medicine and Public Health Preparedness* 3, no. 2 (2009): 88–96, https://doi.org/10.1097/DMP.0b013e3181a6e952
- 55. W.H.O., "WHO | Democratic Republic of the Congo," WHO. World Health Organization, 2016, http://www.who.int/countries/cod/en/
- 56. Here, we do not have quantitative data but speak from experience. One of the primary authors of this report has spent several years researching the health system in Congo; another has operated as a physician in the system for 18 years. See also (Malemo Kalisya 2019).
- 57. Bukonda et al., "Health Care Entrepreneurship in the Democratic Republic of the Congo"; Bwimana, "Health Sector Network Governance and State-Building in South Kivu, Democratic Republic of Congo," December 1, 2017,
- 58. Bertone, Lurton, and Mutombo, "Investigating the Remuneration of Health Workers in the DR Congo: Implications for the Health Workforce and the Health System in a Fragile Setting."
- 59. Interview, traditional practictioner, Beni, 2.25.20.
- 60. Originally, the Allied Democratic Forces, or ADF, were an Islamist rebellion from Uganda that entered DRC in the 1990s. In the past three decades, ADF has become significantly enmeshed in local and regional conflict dynamics and now many of the atrocities attributed to ADF do not necessarily have ties to the original members of the group. For more on ADF, see CRG (2017).
- 61. On fear in the West African epidemic, see Michiel Hofman and Sokhieng Au, eds., *The Politics of Fear: Médecins sans Frontières and the West African Ebola Epidemic* (New York, NY, United States of America: Oxford University Press, 2017).
- 62. Oly llunga Kalenga et al., "The Ongoing Ebola Epidemic in the Democratic Republic of Congo, 2018–2019," *New England Journal of Medicine* 381, no. 4 (July 25, 2019): 373–83, <a href="https://doi.org/10.1056/NEJMsr1904253">https://doi.org/10.1056/NEJMsr1904253</a>. also suggest that Ebola was present in the area several months before the epidemic was declared.
- 63. The contribution of traditional infection control practices to the containment of Ebola has also been documented in past epidemics. See Barry S. Hewlett and Bonnie L. Hewlett, Ebola, Culture, and Politics: The Anthropology of an Emerging Disease, Case Studies on Contemporary Social Issues (Belmont, CA: Thomson, 2008); Barry S. Hewlett and Richard P. Amola, "Cultural Contexts of Ebola in Northern Uganda," Emerging Infectious Diseases 9, no. 10 (October 2003): 1242–48, https://doi.org/10.3201/eid0910.020493
- 64. A similar phenomenon occurred in West Africa, see Nguyen, "Ebola: How We Became Unprepared, and What Might Come Next."
- 65. Interview, nurse A from Mangina Referral Health Center, 2.3.20; Interview, physician from Mangina Referral Health Center, 2.28.20.
- 66. Interview, physician from Mangina Referral Health Center, 2.28.20.
- 67. Interview, nurse A from Mangina Referral Health Center, 2.3.20.
- 68. Interview, nurse B from Mangina Referral Health Center, 2.3.20.
- 69. Interview, nurse B from Mangina Referral Health Center, 2.3.20.



- 70. Indeed, in May 2018, the nurses in the region had gone on an administrative strike—functioning clinically but not sending reports to the central administration—due to several months of unpaid salaries. According to our ethnographic work, these salaries disappeared during a transition to a different banking mechanism and were never recovered, despite significant effort on the behalf of the nursing union. Given that three physicians, who were not involved in the strike, were working in the Mangina health center during this time, the administrative strike did not effect the Ebola epidemic directly. The physicians were in charge of the health center and could have contacted the central health office directly with concerns if they had, indeed, recognized the epidemic and trusted central administrators.
- 71. While the vaccine had been submitted to the FDA and the European Commission, it had not yet been approved. mAb114 was only very early in Phase I trials.
- 72. For a discussion of MEURI protocols for this epidemic, see WHO, "Notes for the Record: Consultation on Monitored Emergency Use of Unregistered Interventions (MEURI) for Ebola Virus Disease," August 27, 2018, <a href="https://www.who.int/ebola/drc-2018/notes-for-the-re-cord-meuri-ebola.pdf">https://www.who.int/ebola/drc-2018/notes-for-the-re-cord-meuri-ebola.pdf</a>
- 73. See also CASS Briefing Note 4 CASS, "Social Science Support for COVID-19: Lessons Learned Brief 4. Social Sciences Evidence on Barriers to Healthcare Seeking during the DRC Ebola Outbreak."
- 74. The dangers of fear-based public health messaging is discussed at length below, and also in Ellie Kemp, "Replacing the Language of Fear: Language and Communication in DRC's Latest Ebola Response," *Humanitarian Practice Network*, March 2020, <a href="https://odihpn.org/magazine/replacing-the-language-of-fear-language-and-communication-in-drcs-latest-ebola-response/">https://odihpn.org/magazine/replacing-the-language-of-fear-language-and-communication-in-drcs-latest-ebola-response/</a>
- 75. Interview, physician from Mangina Referral Health Center, 2.28.20.
- 76. Interview, nyumba kumi in Mangina, 2.3.20.
- 77. According to one MSF staff member with whom we spoke (2.19.20) who had been in Mangina at the beginning of the epidemic, there had been discussion about setting up handwashing and temperature monitoring stations on the roads out from Mangina—especially given that Mangina served as a key hub through which much of the region's agricultural products passed. However, the placement of these stations was initially deferred, in an effort to minimize the coercion and criminalization that these sorts of public health measures tend to produce. By November 2018, when they were erected, Ebola was already widespread.
- 78. Interview, preacher in Beni, 2.8.20.
- 79. Ethnographic work, Beni, 2.2.20.
- 80. The third report in this series will examine in more detail the factors leading to violence against the Response.
- 81. In our survey, we asked several questions to assess which organizations the population trusted in the Ebola Response. In our analysis sessions, we found that these questions were very difficult for much of the population, who often grouped humanitarians and government officials together with the term "the people who come in Land Cruisers [batu ya Land Cruiser]."
- 82. Ethnographic work, Beni, 1.25.20. The third report by CRG on this Response will cover armed escorts in more detail.
- 83. Benton, "Whose Security? Militarization and Securitization During West Africa's Ebola Outbreak."
- 84. The hierarchy of lives mentioned here extended far beyond militarization to affect the provision of contracts, salaries, insurance, and other benefits to some Response staff while denying other staff access to them. This will be explored in more detail in the second CRG report on the political economy of the Response.
- 85. The most commonly spoken language in Kinshasa is Lingala; in the Grand Nord, it is Kiswahili (or Kinande). While some proportion of both populations speak French, only those who have had access to secondary education are actually comfortable in the colonial language.
- 86. This viewpoint is a holdover from colonial times, when the Belgian formed Congolese évolué to be the educated class and gave them power over the uneducated masses. For more on this in Congo, see Hunt, A Nervous State: Violence, Remedies, and Reverie in Colonial Congo., and on the phenomenon more generally, see Frantz Fanon, Black Skin, White Masks, trans. Philcox, Richard (New York: Grove Press, 2008).
- 87. On the problematic temporality of the humanitarian "crisis," see Cathrine Brun, "There Is No Future in Humanitarianism: Emergency, Temporality and Protracted Displacement," *History and Anthropology* 27, no. 4 (August 7, 2016): 393–410, <a href="https://doi.org/10.1080/02757206">https://doi.org/10.1080/02757206</a>.



2016.1207637; Peter Redfield, *Life in Crisis: The Ethical Journey of Doctors without Borders* (Berkeley: University of California Press, 2013). On the way that militarization, and the temporality of urgency more generally, privileges the protection of some people while sacrificing the security of others, see Benton, "Whose Security? Militarization and Securitization During West Africa's Ebola Outbreak."

- 88. MSF, "Medical Activities Suspended after Ebola Treatment Centre Attack | MSF," Médecins Sans Frontières (MSF) International, February 28, 2019, <a href="https://www.msf.org/medical-activities-suspended-after-ebola-treatment-centre-attack">https://www.msf.org/medical-activities-suspended-after-ebola-treatment-centre-attack</a>.
- 89. The second report in this series will explore this dynamic further.
- 90. See Andrew Lakoff, "Two States of Emergency: Ebola 2014," Limn, January 2015, <a href="https://limn.it/articles/two-states-of-emergency-ebo-la-2014/">https://limn.it/articles/two-states-of-emergency-ebo-la-2014/</a>; Lakoff, Unprepared for a fuller discussion of this.
- 91. See WHO, "Report of the External Auditor," May 9, 2019, <a href="https://apps.who.int/gb/ebwha/pdf\_files/WHA72/A72\_39-en.pdf">https://apps.who.int/gb/ebwha/pdf\_files/WHA72/A72\_39-en.pdf</a>. for a discussion of the role of the WHO Health Emergency Program, which was set up after West Africa, during this epidemic.
- 92. The second report in this series will explore this dynamic further.
- 93. While anecdotal, these testimonies should give pause to any celebration of WHO's role as an operational partner.
- 94. Ethnographic work, Furu, 1.22.20.
- 95. Mélanie Gouby, "Ebola: Les Humanitaires Pris Pour Cibles En RDC," *Le Figaro*, January 9, 2020, <a href="https://www.lefigaro.fr/international/ebo-la-les-humanitaires-pris-pour-cibles-en-rdc-20200108">https://www.lefigaro.fr/international/ebo-la-les-humanitaires-pris-pour-cibles-en-rdc-20200108</a>
- 96. See also, Vinh-Kim Nguyen, "An Epidemic of Suspicion Ebola and Violence in the DRC," New England Journal of Medicine 380, no. 14 (2019): 1298–99, https://doi.org/10.1056/NEJMp1902682 for discussion of the "epidemic of suspicion" that prevailed during this time.
- 97. Chad R. Wells et al., "The Exacerbation of Ebola Outbreaks by Conflict in the Democratic Republic of the Congo," *Proceedings of the National Academy of Sciences* 116, no. 48 (2019): 24366–72, <a href="https://doi.org/10.1073/pnas.1913980116">https://doi.org/10.1073/pnas.1913980116</a> gives one account of this particular time in Butembo.
- 98. Susan Scutti, "Congo Ebola Outbreak Not a Public Health Emergency of International Concern, WHO Says," CNN. April 12 (2019), <a href="https://www.cnn.com/2019/04/12/health/ebola-public-health-emergency-congo-africa-bn-intl/index.html">https://www.cnn.com/2019/04/12/health/ebola-public-health-emergency-congo-africa-bn-intl/index.html</a>
- 99. W.H.O., "WHO | Ebola Virus Disease Democratic Republic of the Congo," WHO. World Health Organization, 2020, <a href="http://www.who.int/csr/don/23-january-2020-ebola-drc/en/">http://www.who.int/csr/don/23-january-2020-ebola-drc/en/</a>
- 100. Barry S. Hewlett and Bonnie L. Hewlett, Ebola, Culture, and Politics: The Anthropology of an Emerging Disease. Case Studies on Con temporary Social Issues (Belmont, CA: Thomson, 2008); Barry S. Hewlett and Richard P. Amola, "Cultural Contexts of Ebola in Northern Uganda," Emerging Infectious Diseases 9, no. 10 (2003): 1242–48, <a href="https://doi.org/10.3201/eid0910.020493">https://doi.org/10.3201/eid0910.020493</a>; Alain Epel boin, Approche Anthropologique de l'épidémie de FHV Ebola 2014 En Guinée Conakry (OMS, 2014), <a href="https://hal.archives-ouvertes.fr/hal-01090291">https://hal.archives-ouvertes.fr/hal-01090291</a>
- 101. Here, see Benton, "Ebola at a Distance" for a critique of this practice.
- 102. An internal analysis of the WHO in May 2019 also highlighted the problematic nature of hierarchical, one-way communication during this epidemic: "A recalibration of community engagement around two-way dialogue and adaptation to community feedback is greatly needed" IOAC, "Public Health Emergencies: Preparedness and Response. Report of the Independent Oversight and Advisory Committee for the WHO Health Emergencies Programme," May 2019, <a href="https://www.who.int/about/who\_reform/emergency-capacities/oversight-committee/A72-6-en.pdf?ua=1">https://www.who.int/about/who\_reform/emergency-capacities/oversight-committee/A72-6-en.pdf?ua=1</a>. As had happened in West Africa Benton, "Ebola at a Distance", even the research that was conducted in the community in an effort to create some kind of community feedback was often experienced as exacerbating the Response's already extractive character.
- 103. Paul Richards, *Ebola: How a People's Science Helped End an Epidemic*, African Arguments (London: Zed Books, 2016); Leach and Hewlett, "Haemorrhagic Fevers: Narratives, Politics and Pathways." describe similar dynamics in previous epidemics.



- 104. W.H.O., "Report of the External Auditor."
- 105. Interviews with various WHO Response staff, January to March 2020.
- 106. W.H.O., "Optimized Supportive Care for Ebola Virus Disease: Clinical Management Standard Operating Procedures.," March 2019, <a href="https://apps.who.int/iris/bitstream/handle/10665/325000/9789241515894-eng.pdf?sequence=1">https://apps.who.int/iris/bitstream/handle/10665/325000/9789241515894-eng.pdf?sequence=1</a>
- 107. Sabue Mulangu et al., "A Randomized, Controlled Trial of Ebola Virus Disease Therapeutics," New England Journal of Medicine 381, no. 24 (December 12, 2019): 2293–2303, https://doi.org/10.1056/NEJMoa1910993
- 108. For a discussion of the ring vaccination strategy, which was implemented successfully in the case of smallpox, see Ana Maria Henao-Restrepo et al., "Efficacy and Effectiveness of an RVSV-Vectored Vaccine in Preventing Ebola Virus Disease: Final Results from the Guinea Ring Vaccination, Open-Label, Cluster-Randomised Trial (Ebola Ça Suffit!," *The Lancet* 389, no. 10068 (2017): 505–18, https://doi.org/10.1016/S0140-6736(16)32621-6
- 109. M.S.F., "MSF Begins Administering New Ebola Vaccine in DRC," in *Doctors Without Borders* (USA, 2019), <a href="https://www.doctorswithoutborders.org/what-we-do/news-stories/news/msf-begins-administering-new-ebola-vaccine-drc">https://www.doctorswithoutborders.org/what-we-do/news-stories/news/msf-begins-administering-new-ebola-vaccine-drc</a>
- 110. KST, "Congolese Army's Optimism Undermined by New ADF Massacres," Kivu Security Blog (blog), March 2, 2020, <a href="https://blog.kivusecurity.org/congolese-armys-optimism-undermined-by-new-adf-massacres/">https://blog.kivusecurity.org/congolese-armys-optimism-undermined-by-new-adf-massacres/</a>
- 111. Ethnographic research, Beni, 11.02.19.
- 112. For more on the Congolese state over the past two decades, see Timothy Raeymaekers, Violent Capitalism and Hybrid Identity in the Eastern Congo: Power to the Margins (New York, NY: Cambridge University Press, 2014); Trefon, Reinventing Order in Congo; Jason Stearns, Dancing in the Glory of Monsters: The Collapse of the Congo and the Great War of Africa (New York: PublicAffairs, 2011).
- 113. World Bank, "The World Bank in DRC," World Bank, 2020, https://www.worldbank.org/en/country/drc/overview
- 114. DW, "Congo: Protesters Storm UN Base in Beni," November 25, 2019, https://www.dw.com/en/congo-protesters-storm-un-base-in-beni/a-51407396
- 115. Ethnographic research, Goma, 10.29.19.
- 116. Mosoka P. Fallah et al., "Quantifying Poverty as a Driver of Ebola Transmission," *PLoS Neglected Tropical Diseases* 9, no. 12 (December 31, 2015), <a href="https://doi.org/10.1371/journal.pntd.0004260">https://doi.org/10.1371/journal.pntd.0004260</a>; Ismail O. D. Rashid and Semiha Abdulmelik, eds., *Understanding West Africa's Ebola Epidemic: Towards a Political Economy*, Security and Society in Africa (London: Zed Books, 2017); Kathleen A. Alexander, Claire E. Sanderson, Madav Marathe, Bryan L. Lewis, Caitlin M. Rivers, Jeffrey Shaman, John M. Drake, et al., "What Factors Might Have Led to the Emergence of Ebola in West Africa?," *PLoS Neglected Tropical Diseases* 9, no. 6 (June 4, 2015), <a href="https://doi.org/10.1371/journal.pntd.0003652">https://doi.org/10.1371/journal.pntd.0003652</a>; Compton J Tucker et al., "Climatic and Ecological Context of the 1994-1996 Ebola Outbreaks," *Climatic and Ecological Context of the 1994-1996 Ebola Outbreaks 68*, no. 2 (2002): 147–52; Leach, "The Ebola Crisis and Post-2015 Development"; Barbara Ker stiëns and Francine Matthys, "Interventions to Control Virus Transmission during an Outbreak of Ebola Hemorrhagic Fever: Experience from Kikwit, Democratic Republic of the Congo, 1995," *The Journal of Infectious Diseases* 179, no. Supplement\_1 (February 1, 1999): S263–67, <a href="https://doi.org/10.1086/514320">https://doi.org/10.1086/514320</a>
- 117. One sensitizer stated, "In the trainings, they teach us, don't spend more than 5 minutes in the house, don't eat, don't pee—you just don't want to be accused of somehow giving the family Ebola." Interview, Response sensitizer, 11.2.20.
- 118. Interview, Response staff, 2.28.20.
- 119. The use of the imperative form is, itself, a manifestation of the kinds of structural violence that date back to the colonial period. See Johannes Fabian, *Language and Colonial Power* (Berkeley, CA: University of California Press, 1986).
- 120. See also CASS, "Social Science Support for COVID-19: Lessons Learned Brief 3. Humanitarian Programme Recommendations for COVID-19 Based on Social Sciences Evidence from the DRC Ebola Outbreak Response," May 22, 2020; Translators without Borders, "Missing the Mark? People in Eastern DRC Need Information on Ebola in a Language They Understand. A Rapid Language Needs Assess



ment in Goma, DRC," March 2019, <a href="https://translatorswithoutborders.org/wp-content/uploads/2019/03/DRC">https://translatorswithoutborders.org/wp-content/uploads/2019/03/DRC</a> Ebola Assessment Eng lish.pdf; Translators without Borders, "We Need to Talk. Effective Ebola Risk Communication Requires Respect and Transparency and Remains as Vital as Ever. An Assessment of Changing Communication Needs and Preferences in Beni, North Kivu.," December 2019 for in-depth discussions of the problems that language posed during this epidemic.

- 121. Muyembe-Tamfum et al., "Ebola Outbreak in Kikwit, Democratic Republic of the Congo: Discovery and Control Measures"; Muyem be-Tamfum et al., "Ebola Virus Outbreaks in Africa."
- 122. See also, a discussion in CASS, "Social Science Support for COVID-19: Lessons Learned Brief 1. What Social Sciences Researchers Working in Humanitarian Contexts (Sub-Saharan Africa) Should Be Asking in COVID-19 and Why," May 22, 2020 about this topic.
- 123. William A. Fischer, Timothy M. Uyeki, and Robert V. Tauxe, "Ebola Virus Disease: What Clinicians in the United States Need to Know," *American Journal of Infection Control* 43, no. 8 (2015): 788–93, https://doi.org/10.1016/j.ajic.2015.05.005
- 124. CASS, "Social Science Support for COVID-19: Lessons Learned Brief 3. Humanitarian Programme Recommendations for COVID-19 Based on Social Sciences Evidence from the DRC Ebola Outbreak Response," *UNICEF*, 2020, <a href="https://www.unicef.org/drcongo/media/4131/file/CASS-Brief3-recommendations.pdf">https://www.unicef.org/drcongo/media/4131/file/CASS-Brief3-recommendations.pdf</a>
- 125. Alexandra M. Medley et al., "Case Definitions Used During the First 6 Months of the 10th Ebola Virus Disease Outbreak in the Demo cratic Republic of the Congo Four Neighboring Countries," *Morbidity and Mortality Weekly Report* 69, no. 1 (2020): 14–19, https://doi.org/10.15585/mmwr.mm6901a4
- 126. An independent audit to the WHO commented on the use of force in this context. The report produced by this commission IOAC, "Public Health Emergencies: Preparedness and Response. Report of the Independent Oversight and Advisory Committee for the WHO Health Emergencies Programme"reads, "The combination of broad admission criteria for suspected cases of EVD and delays in getting laboratory confirmation led to a surge of non-Ebola cases being admitted, sometimes in duress by security forces."
- 127. Richards, Ebola.
- 128. Natalie E. Dean et al., "Transmissibility and Pathogenicity of Ebola Virus: A Systematic Review and Meta-Analysis of Household Secondary Attack Rate and Asymptomatic Infection," *Clinical Infectious Diseases* 62, no. 10 (2016): 1277–86, https://doi.org/10.1093/cid/ciw114
- 129. See Esther Yei Mokuwa and Harro Maat, "Rural Populations Exposed to Ebola Virus Disease Respond Positively to Localised Case Handling: Evidence from Sierra Leone," ed. Eric Mossel, *PLOS Neglected Tropical Diseases* 14, no. 1 (January 21, 2020): e0007666, <a href="https://doi.org/10.1371/journal.pntd.0007666">https://doi.org/10.1371/journal.pntd.0007666</a>; Ebola Gbalo Research Group, "Responding to the Ebola Virus Disease Outbreak in DR Congo: When Will We Learn from Sierra Leone?," *The Lancet* 393, no. 10191 (June 2019): 2647–50, <a href="https://doi.org/10.1016/S0140-6736(19)31211-5">https://doi.org/10.1016/S0140-6736(19)31211-5</a>; Nguyen, "Ebola: How We Became Unprepared, and What Might Come Next" for discussions of other locations of Ebola care other than within ETCs.
- 130. Michael T. Osterholm et al., "Transmission of Ebola Viruses: What We Know and What We Do Not Know," *MBio* 6, no. 2 (2015), <a href="https://doi.org/10.1128/mBio.00137-15">https://doi.org/10.1128/mBio.00137-15</a>; Pinzon et al., "Trigger Events: Enviroclimatic Coupling of Ebola Hemorrhagic Fever Outbreaks"; Dean et al., "Transmissibility and Pathogenicity of Ebola Virus: A Systematic Review and Meta-Analysis of Household Secondary Attack Rate and Asymptomatic Infection."
- 131. Leach and Hewlett, "Haemorrhagic Fevers: Narratives, Politics and Pathways"; Pinzon et al., "Trigger Events: Enviroclimatic Coupling of Ebola Hemorrhagic Fever Outbreaks"; Tucker et al., "Climatic and Ecological Context of the 1994-1996 Ebola Outbreaks"; Victor Narat et al., "Rethinking Human—Nonhuman Primate Contact and Pathogenic Disease Spillover," *EcoHealth* 14, no. 4 (2017): 840–50, <a href="https://doi.org/10.1007/s10393-017-1283-4">https://doi.org/10.1007/s10393-017-1283-4</a>; Alexander, Sanderson, Marathe, Lewis, Rivers, Shaman, Drake, et al., "What Factors Might Have Led to the Emergence of Ebola in West Africa?"; Brown and Kelly, "Material Proximities and Hotspots: Toward an Anthropology of Viral Hemorrhagic Fevers: Material Proximities and Hotspots"; Clare Shelley-Egan and Jim Dratwa, "Marginalisation, Ebola and Health for All: From Outbreak to Lessons Learned," *International Journal of Environmental Research and Public Health* 16, no. 17 (2019): 3023, <a href="https://doi.org/10.3390/ijerph16173023">https://doi.org/10.3390/ijerph16173023</a>
- 132. F.A.O., Democratic Republic of the Congo Situation Report April 2020 : FAO in Emergencies, 2020, <a href="http://www.fao.org/emergencies/resources/documents/resources-detail/en/c/1271802/">http://www.fao.org/emergencies/resources/documents/resources-detail/en/c/1271802/</a>



- 133. Pauline Vetter et al., "Ebola Virus Shedding and Transmission: Review of Current Evidence," *Journal of Infectious Diseases* 214, no. suppl 3 (2016): 177–84, https://doi.org/10.1093/infdis/jiw254
- 134. Rojek, Horby, and Dunning, "Insights from Clinical Research Completed during the West Africa Ebola Virus Disease Epidemic."
- 135. N.E. MacDermott and D.G. Bausch, "Virus Persistence and Recrudescence after Ebola Virus Disease: What Are the Risks to Healthcare Workers?," *Journal of Hospital Infection* 94, no. 2 (2016): 113–15, https://doi.org/10.1016/j.jhin.2016.07.004
- 136. Hyojung Lee and Hiroshi Nishiura, "Recrudescence of Ebola Virus Disease Outbreak in West Africa, 2014–2016," *International Journal of Infectious Diseases* 64, no. November (2017): 90–92, <a href="https://doi.org/10.1016/j.ijid.2017.09.013">https://doi.org/10.1016/j.ijid.2017.09.013</a>
- 137. Rojek, Horby, and Dunning, "Insights from Clinical Research Completed during the West Africa Ebola Virus Disease Epidemic," e285.
- 138. Hunt, "An Acoustic Register, Tenacious Images, and Congolese Scenes of Rape and Repetition"; Hunt, A Nervous State: Violence, Remedies, and Reverie in Colonial Congo; Maria Eriksson Baaz and Maria Stern, "The Complexity of Violence: A Critical Analysis of Sexual Violence in the Democratic Republic of Congo (DRC)" (SIDA, May 2010); Charlotte Mertens and Maree Pardy, "'Sexurity' and Its Effects in Eastern Democratic Republic of Congo," Third World Quarterly 38, no. 4 (April 3, 2017): 956–79, <a href="https://doi.org/10.1080/01436597.2016.1191341">https://doi.org/10.1080/01436597.2016.1191341</a>
- 139. Lee and Nishiura, "Recrudescence of Ebola Virus Disease Outbreak in West Africa, 2014–2016"; MacDermott and Bausch, "Virus Persistence and Recrudescence after Ebola Virus Disease: What Are the Risks to Healthcare Workers?"
- 140. Michael Jacobs et al., "Late Ebola Virus Relapse Causing Meningoencephalitis: A Case Report," *The Lancet* 388, no. 10043 (2016): 498–503, https://doi.org/10.1016/S0140-6736(16)30386-5
- 141. Interview, WHO staff, 2.28.20.
- 142. W.H.O., "WHO | Ebola Virus Disease Democratic Republic of the Congo."
- 143. Institute Medicine, Uncertainty and Decision Making: Lessons from Other Public Health Contexts. Environmental Decisions in the Face of Uncertainty (National Academies Press (US, 2013), <a href="https://www.ncbi.nlm.nih.gov/books/NBK200849/">https://www.ncbi.nlm.nih.gov/books/NBK200849/</a>
- 144. Mary Hawk et al., "Harm Reduction Principles for Healthcare Settings," Harm Reduction Journal 14, no. 1 (2017): 70, https://doi.org/10.1186/s12954-017-0196-4
- 145. Ethnographic work, Butembo, 2.6.20.
- 146. See Julie Marcus, "Quarantine Fatigue Is Real. Shaming People Won't Help," *The Atlantic*, 2020, <a href="https://www.theatlantic.com/ideas/archive/2020/05/quarantine-fatigue-real-and-shaming-people-wont-help/611482/">https://www.theatlantic.com/ideas/archive/2020/05/quarantine-fatigue-real-and-shaming-people-wont-help/611482/</a> for a discussion of such communication strategies in COVID-19.
- 147. The overlooking of available *relais communautaires* in the community was potentially made in ignorance of the health system; however, given that the contact tracers were paid relatively well, nepotism also likely motivated the choice to train and hire new staff.
- 148. CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas."
- 149. Ethnographic work, Beni, 2.4.20.
- 150. CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas."
- 151. Ethnographic work, Butembo, 2.15.20.
- 152. See Richards, Ebola. for a discussion of the harmful effects of culturalist understandings of funeral and death during the West



African epidemic. See also P. Formenty et al., "L'épidemie de Fièvre Hémorragique à Virus Ebola En République Du Congo, 2003: Une Nouvelle Stratégie?," *Médecine Tropicale* 63, no. 3 (2003): 291–95; W.H.O., *How to Conduct Safe and Dignified Burial of a Patient Who Has Died from Suspected or Confirmed Ebola or Marburg Virus Disease*, 2017, https://apps.who.int/iris/bitstream/handle/10665/137379/WHO\_EVD\_GUIDANCE\_Burials\_14.2\_eng.pdf?sequence=1

- 153. Epelboin, Approche Anthropologique de l'épidémie de FHV Ebola 2014 En Guinée Conakry; Richards, Ebola.
- 154. Personal communication with Alain Epelboin, 1.21.2020.
- 155. For more on the long-term effects of these errors, see Theresa Jones, Noé Kasali, and Olivia Tulloch, "Grief and Memorialisation: Making Meaning with Ebola-Affected Families," *Humanitarian Practice Network*, March 2020, <a href="https://odihpn.org/magazine/grief-and-memorialisation-making-meaning-with-ebola-affected-families/">https://odihpn.org/magazine/grief-and-memorialisation-making-meaning-with-ebola-affected-families/</a>. See also CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas."
- 156. CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas."
- 157. Natalie Roberts, "Ebola Epidemic in War-Torn Democratic Republic of Congo, 2018: Acceptability and Patient Satisfaction of the Recombinant Vesicular Stomatitis Virus Zaire Ebolavirus Vaccine," *Vaccine* 37, no. 16 (2019): 2174–78, <a href="https://doi.org/10.1016/j.vaccine.2019.03.004">https://doi.org/10.1016/j.vaccine.2019.03.004</a>
- 158. CASS, "Social Science Support for COVID-19: Lessons Learned Brief 3. Humanitarian Programme Recommendations for COVID-19 Based on Social Sciences Evidence from the DRC Ebola Outbreak Response," May 22, 2020; Translators without Borders, "Missing the Mark? People in Eastern DRC Need Information on Ebola in a Language They Understand. A Rapid Language Needs Assessment in Goma, DRC."
- 159. In May 2019, SAGES changed the recommended dose for rVSV-ZEBOV vaccine. For more on this, see WHO, "Report of the External Auditor."
- 160. The fact that rVSV-ZEBOV has such a severe side effect profile makes it a less ideal vaccine; however, given this vaccine's efficacy as it is reported in the Ça suffit! trial, it will be very difficult for other, possibly more ideal vaccines, to make it through clinical trials. This problem is discussed in Kelly, "Ebola Vaccines, Evidentiary Charisma and the Rise of Global Health Emergency Research"; Anton Camacho et al., "Estimating the Probability of Demonstrating Vaccine Efficacy in the Declining Ebola Epidemic: A Bayesian Modelling Approach," BMJ Open 5, no. 12 (December 1, 2015): e009346, https://doi.org/10.1136/bmjopen-2015-009346
- 161. CASS, "Social Science Support for COVID-19: Lessons Learned Brief 2. Gender Inclusiveness in COVID-19 Humanitarian Response Operations, Evidence from Social Sciences Outbreak Research," 2020.
- 162. IRC, "Not All That Bleeds Is Ebola: How Has the DRC Ebola Outbreak Impacted Sexual and Reproductive Health in North Kivu?" reports that Ebola disproportionately affected women and girls during this epidemic (56 percent), and that infected pregnant women had significantly higher rates of mortality than average (53 percent versus 39 percent).
- 163. See Kapur, "Gender Analysis: Prevention and Response to Ebola Virus Disease in the Democratic Republic of Congo." on sexual favors and other gender-based violence during this Response.
- 164. CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas."
- 165. While the vaccination strategy changed in January 2020, vaccines were never given within the public health centers by nurses who gave routine vaccinations. The fact that Ebola vaccination never became integrated into the routine vaccination system, despite community feedback demanding this, profoundly limiting vaccine acceptance during this epidemic.
- 166. In an interview with Merck (1.10.20), the lack of additional vaccine was attributed to the vaccine's long manufacturing process. Per staff at Merck, rVSV-ZEBOV takes 12 months to produce; this epidemic has lasted 23 months.
- 167. There were other components to the parallel system, like isolation centers, etc. However, given that these played a small overall role in the management of the epidemic, we do not consider them here.



- 168. Interview in Butembo, 2.20.20.
- 169. CASS played a pivotal role in making visible the importance of these small, more informal systems to healthcare in the region.
- 170. See IRC, "Not All That Bleeds Is Ebola: How Has the DRC Ebola Outbreak Impacted Sexual and Reproductive Health in North Kivu?" for a discussion about how the triaging tool used in this epidemic proved incredibly dangerous to women's health.
- 171. MSF has argued for the necessity for modified PPE in Ebola treatment. See, for example, Roberts, *Ebola Epidemic in War-Torn Demo cratic Republic of Congo, 2018: Acceptability and Patient Satisfaction of the Recombinant Vesicular Stomatitis Virus Zaire Ebolavirus Vaccine.*
- 172. Based on our interviews and the recently published article Richard Kojan et al., "Reducing Mortality from Ebola through a Comprehensive, Decentralised and Integrated Standard of Care," *Humanitarian Practice Network*, March 2020, <a href="https://odihpn.org/magazine/reducing-mortality-from-ebola-through-a-comprehensive-decentralised-and-integrated-standard-of-care/">https://odihpn.org/magazine/reducing-mortality-from-ebola-through-a-comprehensive-decentralised-and-integrated-standard-of-care/</a>, ALIMA has done similar work, but we did not visit their structures.
- 173. Interview, MSF staff, 2.12.20.
- 174. During this epidemic, MSF France's integrated triage centers were still managed by the Response. As a result, triage was Ebola-specific, only singling out those with Ebola symptoms, instead of a more general form of triage, that also accounted for clinical condition of the patient. See Roberts, "Ebola Epidemic in War-Torn Democratic Republic of Congo, 2018: Acceptability and Patient Satisfaction of the Recombinant Vesicular Stomatitis Virus Zaire Ebolavirus Vaccine"; Annie-Marie Pegg, "Healthcare in the Time of Ebola: Towards an Integrated Syndromic Approach?," n.d., for a description of a rigorous triage system that could save lives during an epidemic as during non-epidemic times
- 175. Both practices documented by our ethnographic teams.
- 176. Because of the potential for a false negative test early in the illness, the ruling out of Ebola requires two tests 48 hours apart.
- 177. CASS, "Social Science Support for COVID-19: Lessons Learned Brief 4. Social Sciences Evidence on Barriers to Healthcare Seeking during the DRC Ebola Outbreak."
- 178. See Sabue Mulangu et al., "A Randomized, Controlled Trial of Ebola Virus Disease Therapeutics," New England Journal of Medicine 381, no. 24 (December 12, 2019): 2293–2303, <a href="https://doi.org/10.1056/NEJMoa1910993">https://doi.org/10.1056/NEJMoa1910993</a>. Certainly more clinical advances have been proposed during this epidemic, which, if instituted, would have positive mortality benefits: the WHO has recommended the use of post-exposure for exposed healthcare workers WHO, "Notes for the Record: Consultation on Monitored Emergency Use of Unregistered Interventions (MEURI) for Ebola Virus Disease"; MSF has made a similar argument for high-risk contacts of people con firmed to have Ebola; in March 2020, ALIMA was working to get dialysis capacity in ETCs; a randomized control trial has been proposed to test the effect of treatment molecules on the eradication of Ebola virus from survivors' sperm.
- 179. Much has written about fear of ETCs—and, in this epidemic, the flight from them Richardson et al., "The Ebola Suspect's Dilemma"; Gomez-Temesio, "Outliving Death: Ebola, Zombies, and the Politics of Saving Lives"; CASS, "Social Science Support for COVID-19: Lessons Learned Brief 4. Social Sciences Evidence on Barriers to Healthcare Seeking during the DRC Ebola Outbreak"; CDC SBS Task Force, "Barriers and Motivators for Community Participation in the Response to Ebola in the Democratic Republic of Congo (DRC), 2018-2019 A Synthesis of Social Science Analysis Results and Corresponding Field Activities in Four Response Areas."; Nguyen, "An Epidemic of Suspicion Ebola and Violence in the DRC."
- 180. After the West African epidemic, ALIMA designed the CUBE, a self-contained Biosecure Emergency Care Unit intended for use in outbreaks of highly infectious disease. With transparent sides and external arm entries, the CUBE allows close monitoring of patients, and even the delivery of clinical care across walls, while also providing maximal protection for healthcare workers. During this epidemic, ALIMA and MSF France used the CUBE for treatment of confirmed Ebola cases.
- 181. UNDP, "Recovering from the Ebola Crisis: A Summary Report," 2015, <a href="https://www.undp.org/content/dam/undp/library/crisis%20prevention/f">https://www.undp.org/content/dam/undp/library/crisis%20prevention/f</a> Ebola-recovery letter Web.pdf
- 182. According to CASS, "Social Science Support for COVID-19: Lessons Learned Brief 3. Humanitarian Programme Recommendations for COVID-19 Based on Social Sciences Evidence from the DRC Ebola Outbreak Response," May 22, 2020, healthcare workers only comprised 5 percent of total infections. The large majority of these were traditional practitioners who were initially excluded from vaccination campaigns.



- 183. In our household survey, which was conducted after free healthcare in most hospitals had ended, 66 percent of households (1012/1541) reported that they visited hospitals more frequently when free healthcare was available. This survey data is supported by CASS data on the increase in consultations during free healthcare CASS, "Social Science Support for COVID-19: Lessons Learned Brief 4. Social Sciences Evidence on Barriers to Healthcare Seeking during the DRC Ebola Outbreak." Similar increases in the frequentation of health structures were seen with the implementation of free care during the 9th epidemic Yuen W. Hung et al., "Impact of a Free Health Care Policy in the Democratic Republic of the Congo During an Ebola Outbreak: An Interrupted Time-Series Analysis," in press, https://doi.org/10.2139/ssrn.3420410
- 184. On the decrease of health structure frequentation in the West African epidemic, see Bolkan et al., "Ebola and Indirect Effects on Health Service Function in Sierra Leone"; Bolkan et al., "Admissions and Surgery as Indicators of Hospital Functions in Sierra Leone during the West-African Ebola Outbreak"; Ibrahim Bundu et al., "Surgery in the Time of Ebola: How Events Impacted on a Single Surgical Institution in Sierra Leone," Journal of the Royal Army Medical Corps 162, no. 3 (June 2016): 212–16, https://doi.org/10.1136/jramc-2015-000582
- 185. While our quantitative data will be presented in full elsewhere, it deserves mention that the one measure in which healthcare seemed to be worse during the Ebola epidemic than before was measles vaccination. In our household survey, only 89 percent (2755/3102) of households stated that they would bring their children in for routine vaccinations during the Ebola epidemic, largely due to fear of con tracting Ebola during vaccination. The central health zones of Butembo, Katwa, Beni, Mabalako, Kalunguta, and Vuhovi together report ed a 14 percent reduction in vaccination rates during the Ebola epidemic compared to a year and a half prior. Despite a large measles vaccination campaign in December 2019, the number of unvaccinated children in North Kivu likely remains dangerously high, according to a source at MSF, especially given the ongoing measles epidemic in the region Tanja Ducomble and Etienne Gignoux, "Learning from a Massive Epidemic: Measles in DRC," *The Lancet Infectious Diseases* 20, no.5 (2020): 542, <a href="https://doi.org/10.1016/S1473-3099(20)30265-6">https://doi.org/10.1016/S1473-3099(20)30265-6</a>. This data has been reported to WHO with recommendation for immediate action. For discussions of the measles epidemic that followed the West African Ebola epidemic, see Balcha Girma Masresha et al., "The Impact of a Prolonged Ebola Outbreak on Measles Elimination Activities in Guinea, Liberia and Sierra Leone, 2014-2015," *The Pan African Medical Journal* 35, no. Suppl 1 (2020): 8, <a href="https://doi.org/10.11604/pamj.supp.2020.35.1.19059">https://doi.org/10.11604/pamj.supp.2020.35.1.19059</a>; Saki Takahashi et al., "The Growing Risk from Measles and Other Childhood Infections in the Wake of Ebola," *Science* 347, no. 6227 (2015): 1240–42, <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4691345/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4691345/</a>
- 186. Adia Benton and Kim Yi Dionne, "International Political Economy and the 2014 West African Ebola Outbreak," *African Studies Review* 58, no. 1 (April 2015): 223–36, <a href="https://doi.org/10.1017/asr.2015.11">https://doi.org/10.1017/asr.2015.11</a> make a similar argument in the West African context, arguing that racist structures of thought, which privileged the protection of white lives over Black lives, underlay much of the failure in that Ebola epidemic.
- 187. This, at a time when that system saw a significant increase in utilization. Given how thinly stretched the healthcare personnel who remained in their posts were, the concerns that CASS has posed about the diminished quality of care within the Congolese health system during this epidemicCASS, "Social Science Support for COVID-19: Lessons Learned Brief 4. Social Sciences Evidence on Barriers to Healthcare Seeking during the DRC Ebola Outbreak" are warranted.
- 188. See especially Margaret E. Kruk, S.Tornorlah Varpilah Michael Myers, and Bernice T. Dahn, "What Is a Resilient Health System? Lessons from Ebola," *The Lancet* 385, no. 9980 (2015): 1910–12, <a href="https://doi.org/10.1016/S0140-6736(15)60755-3">https://doi.org/10.1016/S0140-6736(15)60755-3</a>; Kim J. Brolin Ribacke et al., "Effects of the West Africa Ebola Virus Disease on Health-Care Utilization A Systematic Review," *Frontiers in Public Health* 4 (October 10, 2016), <a href="https://doi.org/10.3389/fpubh.2016.00222">https://doi.org/10.3389/fpubh.2016.00222</a>; Andrew S. Boozary, Paul E. Farmer, and Ashish K. Jha, "The Ebola Outbreak, Frag ile Health Systems, and Quality as a Cure," *JAMA* 312, no. 18 (2014): 1859, <a href="https://doi.org/10.1001/jama.2014.14387">https://doi.org/10.1001/jama.2014.14387</a>
- 189. And this is just the direct economic costs. Caroline Huber, Lyn Finelli, and Warren Stevens, "The Economic and Social Burden of the 2014 Ebola Outbreak in West Africa," *The Journal of Infectious Diseases* 218, no. Supplement\_5 (November 22, 2018): S698–704, <a href="https://doi.org/10.1093/infdis/jiy213">https://doi.org/10.1093/infdis/jiy213</a> suggest that the costs of non-Ebola deaths are actually the largest cost to the system, at \$18 billion, with a comprehensive economic and social burden of the outbreak estimated at \$53 billion.
- 190. Phone call, WHO staff in the Response, 3.30.20.
- 191. See Mobula et al., "Recommendations for the COVID-19 Response at the National Level Based on Lessons Learned from the Ebola Virus Disease Outbreak in the Democratic Republic of the Congo."
- 192. Maxwell J. Smith and Ross E.G. Upshur, "Ebola and Learning Lessons from Moral Failures: Who Cares about Ethics?: Table 1," *Public Health Ethics*, 2015, 10, <a href="https://doi.org/10.1093/phe/phv028">https://doi.org/10.1093/phe/phv028</a>
- 193. Smith and Upshur, "Ebola and Learning Lessons from Moral Failures: Who Cares about Ethics?: Table 1."
- 194. We thank an anonymous peer reviewer for this insight. Although this phrase is often attributed to MSF, it was also part of WHO's self-image during the Response.



- 195. While this epidemic also affected the Ituri province, the funding for this project was specifically directed towards research in North Kivu. As a result, Ituri is not included in the data collection or this analysis.
- 196. The team was composed of five ethnographers: three men and two women, one expatriate, and four from eastern Congo.
- 197. These were Kirotshe, Masisi, Nyiragongo, and Rutshuru. However, this part of the research was cut short due to the COVID-19 pandemic.
- 198. CASS, "Social Science Support for COVID-19: Lessons Learned Brief 1. What Social Sciences Researchers Working in Humanitarian Contexts (Sub-Saharan Africa) Should Be Asking in COVID-19 and Why."



**The Congo Research Group (CRG)** is an independent, non-profit research project dedicated to understanding the violence that affects millions of Congolese. We carry out rigorous research on different aspects of the conflict in the Democratic Republic of the Congo. All of our research is informed by deep historical and social knowledge of the problem at hand. We are based at the Center on International Cooperation at New York University.

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