

PLANNING FOR POST-EBOLA

LESSONS LEARNED FROM DR CONGO'S 9TH EPIDEMIC



The author

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ACRONYMS AND ABBREVIATIONS

| | |
|---------------|--------------------------------------------------------------------------------------------------|
| AC | Community Animators (<i>Animateur Communautaire</i>) ¹ |
| ALIMA | Alliance for International Medical Action |
| ANVE | National Association of Ebola Vanquishers (<i>Association National des Vainqueurs d’Ebola</i>) |
| APS | Psycho-social assistant (<i>Assistant Psycho-social</i>) |
| AT | Territorial Administrator (<i>Administrateur du Territoire</i>) |
| CAC | Community outreach units (<i>Cellule d’Animation Communautaire</i>) |
| CBO | Community-based organization |
| CE | Community engagement |
| CODESA | Local health committees (<i>Comité de Développement de l’aire de Santé</i>) |
| DPS | Provisional health division (<i>Division Provinciale de Santé</i>) |
| EP | Protective equipment (<i>équipement protective</i>) |
| ETC | Ebola Treatment Center |
| EVD | Ebola Virus Disease |
| FPIC | Free prior and informed consent |
| INRB | National Institute of Biomedical Research (<i>Institut National de Recherche Biomédicale</i>) |
| MPH | Ministry of Public Health |
| MCZ | Medical Inspector of the Health Zone (<i>Médecin Chef de Zone</i>) |
| MSF | Doctors Without Borders (<i>Médecins Sans Frontières</i>) |
| PA | Indigenous people (<i>Peuple Autochtone</i>) |
| PBF | Performance-based financing |
| PPE | Personal protective equipment |
| RCCE | Risk communication and community engagement |
| RECO | Community health workers (<i>relais communautaire</i>) |
| SANRU | Rural Health Program (<i>Projet Santé Rurale</i>) |
| SDB | Safe and dignified burial |
| UNDP | United Nations Development Programme |
| UNICEF | United Nations Children’s Fund |
| USAID | United States Agency for International Development |
| WHO | World Health Organization |
| WFP | World Food Programme |

¹ The original French terms are written in italics and in parentheses.

EXECUTIVE SUMMARY

This report is for supervisors managing ongoing Ebola outbreaks, or working on preparedness and recovery activities in regions at risk of, or affected by, Ebola epidemics. It is based on rapid and intensive ethnographic field research in Equateur Province, Democratic Republic of Congo, undertaken less than a month after the epidemic was declared over in July 2018. The research comprised 60 separate open-ended, semi-structured interviews with local health workers, government officials and administrators, Ebola survivors and their families, community leaders, and national and international responders.

The overall finding of the report is that an Ebola epidemic, along with the way the response itself is conducted, can have significant social, psychological, economic, and health impacts for the communities involved. By providing a close, qualitative reportage on perceptions of the epidemic and the response in Equateur Province, the report aims to render tangible the social, political and economic dimensions of an Ebola epidemic and to offer recommendations for the response which prepare communities for life ‘post-Ebola’ at each stage of an intervention.

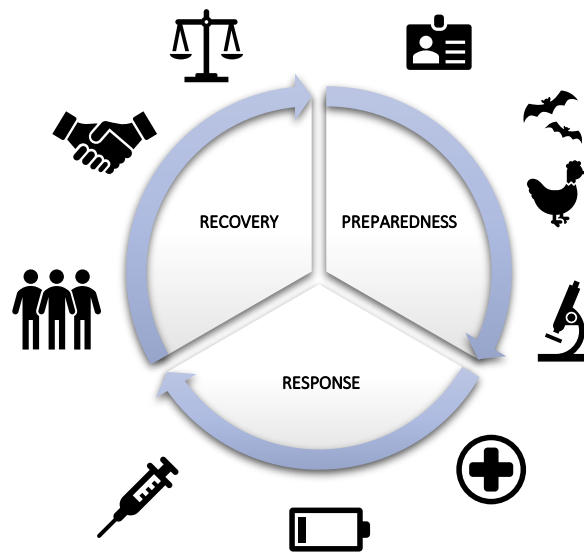
Epidemic management focuses on what needs to be done before, during and after an epidemic in order to minimize the health, social and economic impacts of the epidemic. Each section of the report examines one of these temporal stages. **Part One: Preparedness** provides information and recommendations on emergence, surveillance and health system capacity, vulnerable and marginalized populations, and the political and economic context of the 2018 Equateur outbreak. **Part Two: Response** provides information and recommendations on transmission, risk communication, contact tracing, vaccine deployment, case management, and burials. **Part Three: Recovery** provides information and recommendations on the economic, health (including mental health), and social repercussions of the epidemic and response. An index can be found at the end of the report to locate cross-cutting themes covered in multiple sections.

The report provides recommendations relevant for supervisors working on risk communication, coordination, surveillance and contact tracing, infection prevention and control, case management, and safe & dignified burials (SDBs). Recommendations are divided into those that are operational (i.e. immediately applicable in the event of an outbreak) and those that are orientated toward long-term capacity building. Key recommendations are presented at the beginning of each section and are brought together in the overall conclusion.





The report proposes a **Grassroots Model for Epidemic Response**, based on four key principles: (1) **A ‘whole society’ approach** that attends not only to those individuals directly affected by the outbreak, but also to their broader communities; (2) **a commitment to inclusivity** appreciates that ‘communities’ are not homogenous, and prioritizes the engagement of marginalized and vulnerable populations; (3) **an attention to local stakes** that can help responders appreciate why Ebola epidemics are understood through the lens of broader issues such as politics, economics and religion; and finally, (4) **a commitment to utilizing pre-existing epidemic response capacity** in order to coordinate an effective response and ensures that interventions build on the social and cultural resources of the communities they seek to support.

PLANNING FOR POST-EBOLA

Epidemic management focuses on what needs to be done before, during and after an epidemic. Each section of the report examines one of these temporal stages. During 'preparedness', the focus is on reducing vulnerability to disaster and strengthening capacity, surveillance and early detection. 'Response' begins with a coordinated and rapid investigation, and then the implementation of appropriate control and case management, which is supported at each step and in every aspect by robust, clear and two-way communication. Finally, 'recovery' focuses on evaluation and accompanies affected communities in their lives 'post-Ebola.' Each stage should seek to minimise the health, social and economic impacts of the epidemic.



GRASSROOTS MODEL FOR EPIDEMIC RESPONSE

-  (1) A **'WHOLE SOCIETY' APPROACH** attends not only to those individuals directly affected by the outbreak, but also to their broader communities.
-  (2) A **COMMITMENT TO INCLUSIVITY** appreciates that 'communities' are not homogenous and prioritizes the engagement of marginalized and vulnerable populations.
-  (3) **ATTENDING TO LOCAL PERSPECTIVES** can help responders appreciate why Ebola epidemics are understood through alternative lenses and broader issues, such as politics, economics and religion.
-  (4) **UTILIZING PRE-EXISTING EPIDEMIC RESPONSE CAPACITY** ensures that interventions build on the social and cultural resources of the communities they seek to support.

INTRODUCTION

The Democratic Republic of Congo's ninth Ebola epidemic was declared on 8 May 2018 and was one of the most challenging outbreaks the country has had to face. It emerged simultaneously in two rural health zones, and quickly reached the provincial capital of Mbandaka, a city of more than 1.2 million inhabitants located on the banks of the Congo River and with regular movement along fluvial routes to and from the capital city, Kinshasa, which has over 12 million inhabitants.

Following an epidemiological investigation, the Ministry of Public Health (MPH) and its international partners (including WHO, MSF, UNICEF, IFRC and ALIMA) rapidly deployed to the region, working with national and local partners.

The outbreak was declared over on 24 July 2018. There had been a total of 54 probable and confirmed cases and 33 deaths. The rapid deployment of the response, the active participation of the community and use of the rVSV-ZEBOV-GP trial vaccine were all credited with the rapid containment of the epidemic.

Plans were laid out to continue supporting affected communities for 6 months following the end of the epidemic, in order to stimulate recovery and build resilience. However, on 1 August 2018, a new outbreak was declared in Nord Kivu, and many resources were diverted to support the response efforts there.

PROBLEM STATEMENT

UNICEF played an active role in the response, working on each of the 8 pillars: logistics; surveillance; vaccination; laboratory testing; prevention; case management; communication; psycho-social support.

UNICEF C4D Risk Communication and Community Engagement (RCCE) teams were integrated into the other 7 pillars and were essential for their success. For example, as vaccination teams prepared for deployment, communication experts visited families and broader village communities or urban

neighborhoods, to inform them of the event, what to expect, and to encourage their participation; communication experts were also embedded in surveillance teams, explaining Ebola symptoms and the principles of contact tracing, to assure cooperation; as part of safe & dignified burial teams, communications teams established dialogue which could bridge stringent medical protocols and strong funerary traditions.

Communities can play a significant role in containing Ebola when **two-way communication** is fostered with response workers and where epidemiologists provide timely and relevant advice to local actors. The resulting dialogue makes 'communities think like epidemiologists, and epidemiologists ...think like communities'.²

Despite the ongoing outbreak in Nord Kivu, UNICEF is committed to continuing support for affected communities in Equateur. Furthermore, it is committed to spearheading an approach to Ebola responses which places an emphasis, both before and during each stage of the response, on preparing communities for life *after* the epidemic.

Far less funding is available for recovery, resilience-building and preparedness after an outbreak than during an active epidemic. As such, many important questions remain unanswered:

- What are the enduring social, economic and health impacts of an Ebola epidemic?
- How do local health actors and community members themselves see the successes or challenges of the response?
- What insights do they offer which could improve future response efforts?

OBJECTIVES & SCOPE

The overall objective of this report is to take a 'lessons learned' approach to the epidemic in order to provide recommendations for best practice at each stage of an Ebola outbreak.

An essential element of emergency management is evaluation. This report (using social science methods which act as an extension

² Richards (2016).

of the two-way communication fostered by C4D teams during the response) has sought to develop recommendations in collaboration with the people of Equateur Province.

By providing a close, qualitative reportage on perceptions of the epidemic and the response in Equateur Province, the report aims to render tangible the social, political and economic dimensions of an Ebola epidemic and to offer recommendations which ensure that interventions build on the social and cultural resources of the communities they seek to support – preparing them for life ‘post-Ebola’ at each stage of an intervention or response.

It provides recommendations relevant for supervisors working on risk communication, coordination, surveillance and contact tracing, infection prevention and control, case management, and safe & dignified burials (SDBs).

Recommendations are divided into those that are operational (i.e. immediately applicable in the event of an outbreak) and those that are orientated toward long-term capacity building.

METHODOLOGY

Employing rigorous data collection procedures, the author and a research assistant employed a qualitative approach to gather data both on the ground in Equateur Province (from 25 August until 11 September 2018) and through phone calls and meetings out of country. A thorough literature review of relevant policy pieces and grey literature was also undertaken.

Interviews: A total of 87 people were interviewed during 60 separate open-ended, semi-structured interviews. Interviews typically lasted 45-90 minutes and were conducted in French or Lingala as requested by the interviewee (without the use of an interpreter, as both the author and research assistant speak these languages fluently).

Ethnographic approach: Informal conversations and exchanges were had with local community members and health workers and national or international responders, in order to have a wide range of popular and political speech, behaviors, events, reactions, and representations to analyze.

Participants: The aim was to speak with a broad cross-section of actors in both rural and urban communities. The map below indicates the villages in which interviews were undertaken (in all 5 affected health zones). Research participants can be categorized according to the following:

- Local health officials and community health workers and committee members (RECO, CAC, CODESA): n=31
- Ebola survivors and their families, as well as the families of victims: n=23
- Marginalized populations (Twa): n=15³
- Local leaders (village chiefs, religious leaders, presidents of agricultural associations): n=8
- International responders: n=8
- Government officials and administrators: n=5

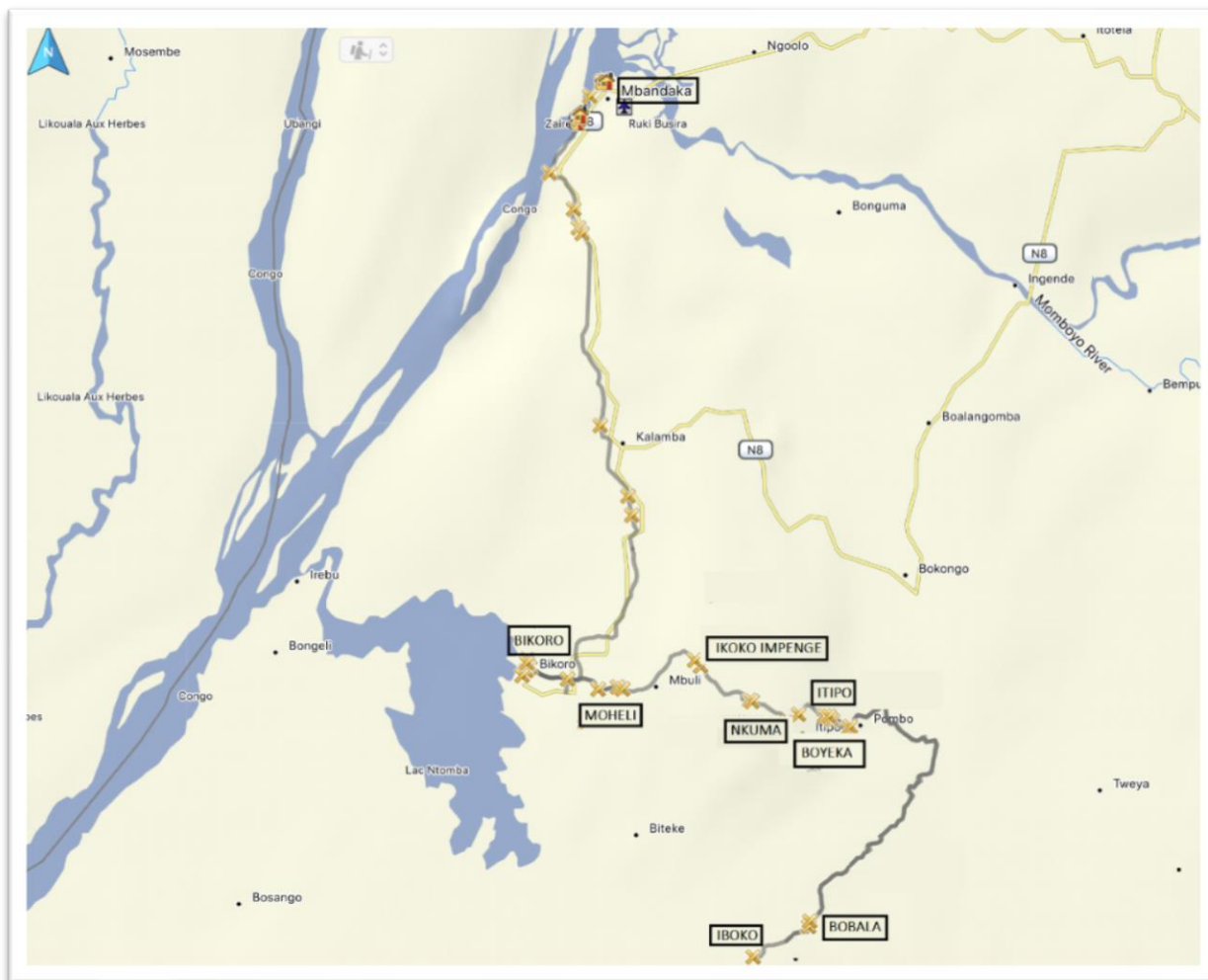



Location: Ethnographic research was conducted in all 5 affected health zones: the health zones of Wangata, Mbandaka and Bolenge (in and around the provincial capital of Mbandaka), and the health zones of Bikoro and Iboko (Territory of Bikoro).

Interviews and ethnographic research were conducted in the city of Mbandaka, the town of Bikoro, and the villages of Moheli, Ikoko Impenge, Nkuma, Itipo, Boyeka, Bobala and Iboko (see map overleaf).

³ These numbers exceed the total number of people (87), by 3 because 3 of the Twa participants were also local leaders or community health workers..

Map showing GPS tracklog of research conducted in Equateur Province 25 Aug – 11 Sept 2018



25KM 

GRASSROOTS MODEL FOR EPIDEMIC RESPONSE

This report proposes a Grassroots Model for Epidemic Response., which has four key principles. The first is a ‘whole society’ approach that attends not only to those individuals directly affected by the outbreak, but also to their broader communities. Doing so can minimize fear, stigmatization and resentment, and help to rebuild social fabrics fragilized during the epidemic.

The second is a commitment to inclusivity which appreciates that ‘communities’ are not homogenous and prioritizes the engagement of marginalized and vulnerable populations. This includes an attention to gender, to inter-

generational dynamics, to ethnic, religious or caste minorities, and to vulnerable populations such as widow(er)s, pregnant women, the infirm and the elderly.

The third is that attention to local stakes can help responders appreciate why Ebola epidemics are understood through the lens of broader issues such as politics, economics and religion. Previously classed as ‘rumors’, these alternative explanations are often very revealing about perceptions of the state and health system, and about social tensions. Attending to these dynamics is of the utmost importance for a successful epidemic response.

Finally, a commitment to utilizing pre-existing epidemic response capacity ensures that

interventions build on the social and cultural resources of the communities they seek to support.

LIMITATIONS

It is imperative that further research is conducted within the next year to monitor and evaluate the social, psychological and economic conditions of affected communities in Equateur Province, as this research provides only a snapshot.

The sample (n.87) is not large enough to be generalizable, especially as there we found some differences in perceptions and experiences based on the location of the research. However, the themes which have been highlighted in this report are those which came up again and again, and also reflect issues raised by communities affected by the 2014 Ebola epidemic in nearby Boende.⁴

The nature of rapid research means that both the sample size and the depth of ethnographic research are limited. Traditional healers were not interviewed, because they were the focus of another C4D research mission.

Furthermore, interviews with members of the national and international response were limited, as many of these actors were occupied with the ongoing outbreak in Nord Kivu and unavailable for interview for this report. The findings highlight several community perspectives and the

recommendations are undoubtedly different than if they had resulted from interviews with responders.

OUTLINE OF THE REPORT

Epidemic management focuses on what needs to be done before, during and after an epidemic in order that the health and economic impacts are minimized. Each section of the report examines one of these temporal moments

Part One: 'Preparedness' provides information and recommendations on emergence, surveillance and health system capacity, vulnerable populations, and the political and economic context of the 2018 Equateur outbreak.

Part Two: 'Response' provides information and recommendations on transmission, risk communication, contact tracing, vaccine deployment, case management, and burials.

Part Three: 'Recovery' provides information and recommendations on the economic, health (including mental health), and social repercussions of the epidemic and response.

Each section begins with an infographic which summarizes the key recommendations. An index can be found at the end of the report to locate cross-cutting themes covered in multiple sections.

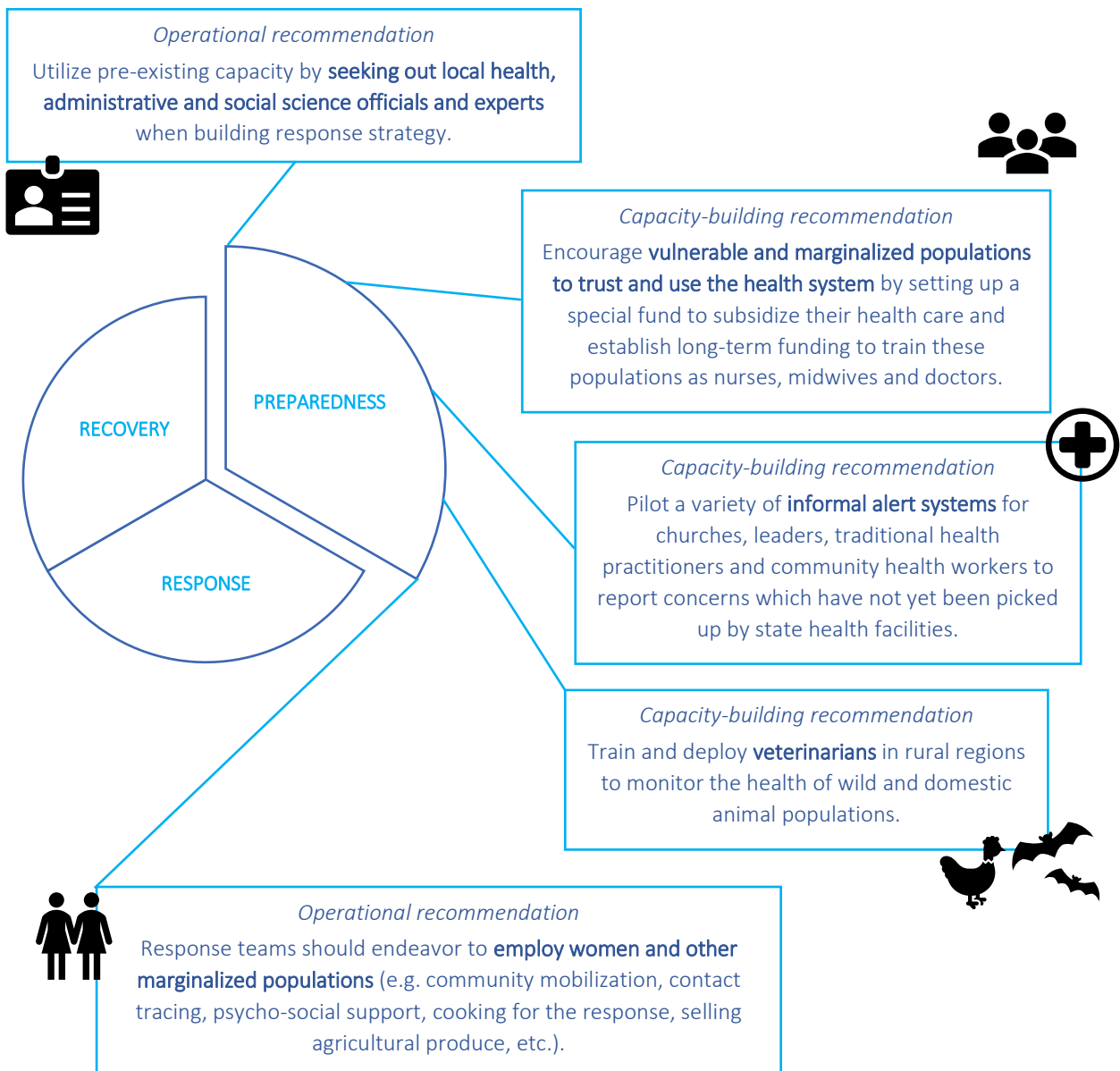
⁴ Alcayna-Stevens & Giles-Vernick (forthcoming); Alcayna-Stevens (forthcoming).

PART I | PREPAREDNESS



PLANNING FOR POST-EBOLA: PREPAREDNESS

Epidemic preparedness constitutes all the activities that must be undertaken at multiple levels (from the national to the health facility level) to be ready to respond effectively to an outbreak. Epidemic preparedness ensures that the routine surveillance system can detect an outbreak as soon as it occurs, and that staff are organized to confirm, investigate, and respond to an outbreak. Stocks of drugs and essential equipment, emergency finances, materials and supplies should also be maintained as part of epidemic preparedness. This section provides detail on the kinds of preparedness which would have facilitated an earlier detection of Ebola in the 2018 Equateur outbreak, as well as a more coordinated early response and a greater level of community engagement in the early stages of the outbreak. Outlined below are the key recommendations.



1. PREPAREDNESS

1.1 UNPACKING ‘COMMUNITY’

Response teams often refer to the local people with whom they work using the concept of ‘community.’ This may also be a salient concept for the people with whom they work themselves; for example, in Equateur Province, ordinary people often refer to themselves as part of ‘*la communauté*,’ using the French term. The term will be used throughout this report. However, it should always be used in a way which does not overlook the fact that rural villages and urban neighborhoods are made up of many different populations with different needs – some of which are more vulnerable than others. The following section therefore outlines the issues faced during an epidemic by some of the most marginalized and vulnerable populations. It provides recommendations for effective engagement of these populations.

1.1.1 DEMOGRAPHY & CAPACITY

The population of Equateur Province is 2,543,936. Half of the population live in the provincial capital of Mbandaka, located on the Congo River along an important trade route which connects to Central African Republic, the Republic of Congo and DRC’s capital, Kinshasa. The population of Mbandaka City is ethnically diverse, and more than 40 languages are spoken in and around Mbandaka.⁵

Valuable information about the population, ethnicity, health and education structures and more can be found in the administrative and governmental ministries and departments. Despite this, some of the earliest reports produced by response teams contained errors and omissions in demographics and maps.⁶

These errors were to do with the speed at which the initial contextual reports needed to be issued. However, they could have been avoided if local administrative and health authorities had been enlisted to help in their production.

Response teams should coordinate with local government structures to access information about the socio-political and economic context, and work with local social scientists (such as those working at the universities and technical colleges of Mbandaka) to determine whether there are important ethnic or political conflicts in the region which could affect the response strategy.

1.1.2 ETHNIC MINORITIES

During the early stages of the Equateur outbreak, response teams expressed concern about ‘resistance’ to the response from an ethnic group they referred to as ‘pygmies’ or ‘Twa’.⁷ Both of these terms can be used pejoratively or derogatorily and thus become offensive to such communities, depending on the context in which they are used.

Response teams should always refer to people by the name they prefer. Using the term ‘pygmies’ further stigmatizes and alienates vulnerable and marginalized populations.

The term ‘PA’ or ‘*peuples autochtones*’ (indigenous people) should be used by response teams. These people often refer to themselves as ‘Twa’.⁸ However, the term ‘PA’ was identified by people who participated in this research (both Twa and non-Twa) as the most respectful form of address for Twa people. This term may change or be disregarded in later years but should be used by response teams in the meantime as a sign of sensitivity and respect.⁹

In this report, I use the term ‘Twa’ (pl. Batwa), which is more prominent in the literature. However, during all research interviews with both Twa and non-Twa, the term ‘PA’ was used.

In terms of ethnic identity, both Twa and non-Twa (called ‘Nkundo’ or ‘Bantu’ by Twa),¹⁰ identify as members of either the Ntomba (to the

⁵ Alcayna-Stevens & Bedford (2018).

⁶ Yong (2018).

⁷ Anoko & Falero (2018).

⁸ The complex history of migration and inter-ethnic relations is beyond the scope of this paper. Cf. Hulstaert (1961); Vansina (1965); Pagezy (1975); Sulzmann (1986); Duda (2018).

⁹ The use of this politically-correct term is to denote respect and is not an indication of Twa ethnic identity.

¹⁰ Both terms are confusing, as they denote a linguistic group (Bantu) of which Twa are a part, and an ethnic group (Nkundo) which is found further east. Cf. Duda & Alcayna-Stevens (2018).

west) or Ekonda (to the east) ethnic groups. They share the same language – either Lontomba or Lokonda.

Rather than a separate ethnic group with a distinct language, it can be useful to think of Batwa as a distinct *caste*. Twa families have a relationship of interdependence with Nkundo/Bantu families, often providing hunted meat or agricultural labor for a Nkundo/Bantu family in exchange for money or agricultural produce and Twa villages are often found on the outskirts Bantu/Nkundo villages.¹¹

Batwa are often marginalized by Nkundo/Bantu; they are paid less for the same work, physically and sometimes verbally harassed or assaulted (with little legal recourse) and excluded from political activity and engagement. Bantu/Nkundo families may refer to themselves as the masters (*nkolo* in Lingala) of Twa lineages, and one young Twa woman described this relationship to us in terms of slavery and colonialism. In her words:

“They colonise and enslave us”

When bushmeat was highlighted as the source of the Ebola (EVD) outbreak, some Batwa hunters told us they had experienced stigmatization. Furthermore, the emergence of EVD cases in Ikoko Impenge was initially connected by the families involved to a family land dispute, in which it was said that one family had sought the services of a powerful Twa healer, who had put a curse on the other family. The family of this man continues to be almost totally ostracized by the Nkundo villagers to this day.¹²

One of the primary reasons Batwa gave for their initial resistance to the response was their suspicion that Ebola was a fabrication which Nkundo/Bantu would use to get rich, while killing or sterilizing Batwa. This led them to resist tests, vaccinations, treatment at biomedical facilities and Ebola Treatment Centers (ETCs), and secure burials. They also found free health care suspicious and initially refused to attend health centers and posts.

Due to a combination of poverty, to the fact that there are few health posts in all-Twa villages, to discrimination experienced at biomedical

facilities, and to their own skills in traditional healing, Twa communities typically have little faith in biomedicine.

A further barrier to their engagement was the fact that many community health actors are Nkundo/Bantu. Nkundo/Bantu – often more educated and more comfortable in expressing themselves to foreigners – became mediators in response teams’ interactions with Twa communities, and this made them distrustful and resentful that they were not being directly engaged by the response.

Speaking retrospectively about the epidemic, many Batwa appeared resentful of the fact that few of them had been directly involved in the response’s activities. Other reports by social scientists suggest that they were often engaged for unpaid services.¹³ Even those who had been involved as community health workers (RECO), reported being underpaid compared with Nkundo/Bantu counterparts. Some families of victims also reported not receiving the psychosocial support and food provisions that bereaved Nkundo/Bantu families received.

Response teams were not always sympathetic to these feelings of exclusions, with some responders explaining that Batwa do not ‘put themselves forward’ or that they do not ‘plan ahead’. The egalitarian nature of Twa societies, which often lack stable customary chiefs, can make it more difficult for response teams to immediately identify clear community leadership and representation.

Even when they were employed by response teams, there were challenges. One international doctor explained that he had employed a Twa man as a security guard, but that the man was physically attacked when he tried to stop a Nkundo/Bantu man from entering the compound; the man said, ‘a Twa has no right to restrict my movement.’

Operational recommendation¹⁴

» No community actor should be asked to work without appropriate payment and all people should be remunerated at the same rate, with direct payment, rather than the use of intermediaries.

¹¹ Duda & Alcayna-Stevens (2018); see also Samndong (2016).

¹² Ingrid Gercama (pers. comm. 2018)

¹³ Duda (2018)

¹⁴ Further, detailed recommendations on working with marginalized Twa communities can be found in Duda & Alcayna-Stevens (2018).

Capacity-building recommendation

» **Support the Ministry of Public Health to reinforce trust in biomedical services by establishing a special fund to subsidize healthcare for Batwa and long-term funding to train Twa nurses, midwives and doctors.**

1.1.3 GENDER

In general, women are more emancipated in Mbandaka City than in the villages (i.e. more likely to pursue an education or own small businesses). Still, very few women hold government positions. The majority are engaged in commerce (most market sellers are women) and unpaid domestic labor. In rural areas several women's agricultural associations exist, where women take turns working in each other's fields.

Women are often important decision makers in the domestic sphere. Whether or not they control part of the household's finances varies between families. However, they are always important actors in ensuring family health and hygiene and in educating children about sanitation, health and disease. Their influence should never be overlooked during an epidemic response. One woman, a leader of women's associations in Itipo, quoted the famous saying, as she explained to me the significant role women play in rural Congo:

"If you educate a woman, you educate a whole nation"

Women are also at higher risk of catching Ebola (EVD) – not due to any biological reason, but because of their social duties.¹⁵ They are often the ones who butcher meat when preparing meals for the family, or when selling bushmeat at market (most vendors of meat and agricultural produce are women). They are also caregivers to the sick and must wash the bodies of deceased female relatives. Pregnant women have been found to be more susceptible to EVD because of their lowered immune systems, and yet they are not eligible to be vaccinated.¹⁶

Widows are often particularly vulnerable members of the community, and likely to be excluded from social and political process. Without their husband, they can face ostracism in their marital village – this is often particularly

acute if their children have already grown and left or if they have no children. Ebola widows face particular challenges. For example, during the mourning period following their husband's death, widows must grieve and cannot leave the house or even stand up to wash or feed themselves for several days. Widows who participated in the research in both rural and urban areas said this meant that they had not been able to attend the vaccination campaign for contacts. Furthermore, widows often struggle to provide for their families without their husband's income, and may even find themselves with debts left by their husbands. *See also, 3.1.4 Debt and funerary costs.*

Women are seldom as influential in the public sphere as in the private sphere, as most ethnic groups in Equateur practice patrilocal residence and women therefore lack family support networks in their marital villages. This can lead to them being overlooked by response teams both in terms of community engagement and in terms of employment opportunities in the response.

Several influential women (including the president and secretary of the women's associations of Itipo and the head of the women and families service in Bikoro) participated in the research. These women felt that there had not always been sufficient engagement of local women in the response. They pointed to an absence of workshops and education sessions targeted specifically at women, and to the fact that many education materials were communicated in French or Lingala, and therefore not always accessible to women, who often have lower levels of education and literacy. This was also an issue with the vaccine consent forms, which were often written in French.

To engage women effectively, sessions should be held in their natal language, and in a setting in which they feel comfortable seeking clarifications, which is not always the case in mixed-gender meetings.

Several women (many of them teachers) were trained as psycho-social assistants by UNICEF partners and were invaluable in efforts to combat stigma and reintegrate survivors and families of victims.

¹⁵ Menendes et al (2015).

¹⁶ Bebell et al (2017).

Operational recommendations

» Response teams should collaborate with local women's associations in order to provide information sessions for women on health, hygiene and risk management, with special information sessions held for pregnant and lactating women to inform them about risk and to explain to them why they are excluded from the vaccine campaign.

» Response teams should endeavor to employ women in various domains (e.g. community mobilization, contact tracing, psycho-social support, cooking for the response, selling agricultural produce, etc.).

1.1.4 YOUTH

The DRC has a markedly young population, with around 42% of the population under the age of 15 years, and 62% under the age of 25 years.

At the beginning of the Equateur outbreak, many parents removed their children from school, fearing that they might be exposed to infected individuals. This was detrimental both to community engagement and to the children's education. Once they started attending classes again, children were provided with education on hand-washing and learned about the disease – they were able to cascade learning to their families.

School teachers should be provided with basic psychosocial skills to support their pupils, and school should be used to engage children using appropriate participatory methods to teach them about the disease, how to protect themselves, and about treatment and vaccination.

Foreign actors and increased economic activity are seen by young people (particularly young men) as opportunities to find employment and piecemeal work. Many will look for opportunities to work for or alongside response teams (helping with logistics or manual work).

It is important to note, however, that, as new employment opportunities for youth have led to greater financial emancipation from their elders, traditional leadership structures have been increasingly challenged, and inter-generational tensions may result in challenges for participatory decision-making (e.g. if elders reject the presence of foreigners whilst youth welcome them in the hope of employment opportunities).

Operational recommendation

» The response should positively harness youth groups and other associations to support and contribute to community mobilization, contact tracing, safe and dignified burials, and to help with logistics including clearing roads. Collaboration can be established with existing youth groups and associations.

1.2 POLITICAL ECONOMY

The following section summarizes the political and economic context of Equateur Province. It examines the structures of governance which must be respected by response teams and provides recommendations on how to remain politically neutral. It also examines the economic activities (subsistence farming, bushmeat hunting and trade etc.) which can be perturbed by a large-scale economic response, and the economic conditions of poverty which can lead communities at large to view an Ebola outbreak less as an issue of public health and more as an issue of wealth and inequality.

1.2.1 GOVERNANCE AND POLITICS

The DRC is divided into 26 provinces, each governed by a provincial government led by a Governor, Vice Governor, and Provincial Ministers (e.g. of agriculture). Each province is subdivided into territories and sectors. The highest administrative authority at the territory level is the territorial administrator (AT). Within a territory, each sector is governed by a sector chief (*Chef de Secteur*).

Rural areas have a parallel governance structure of both state and customary political leadership. Within each sector are several '*groupements*', governed by a *Chef de Groupement* who is also a customary leader and can deal with both legal and customary matters at the groupement level. Within each groupement there are villages, each of which has a *Chef de Village* who is elected by the village to serve as the representative of the state for the village for several years, and several village elders (the heads of each family).

Other influential local elites include religious leaders, local civil society actors and the presidents of farming, youth, church and women's associations. Several of the people who participated in the research felt that there was too much of an emphasis on engaging health actors, and that local leaders, particularly in smaller villages, had not been sufficiently engaged. This was particularly true of Twa leaders.

Complex and cumbersome bureaucratic processes, many of which originate in the colonial period, mean that offense can be taken if influential local leaders, especially those in charge of the structures a response team is attempting to access, are not saluted, informed and engaged from the outset.

Corruption, nepotism and embezzlement are part of the survival strategies of those in positions of power in DRC. Particularly in rural areas, salaries are often unpaid for lengthy periods, and people capitalize on the access and benefits they

can acquire from their position in order to survive. These practices have led to an erosion of trust, and many ordinary Congolese are suspicious and distrustful of the structures through which response teams may attempt to access them. Even at a more local level, inadequate accountability mechanisms mean that elites may monopolize political leadership and benefit from resources meant for community-based organizations.

Both governing and opposition parties often try to politicize an epidemic (and the resources it brings to the country), and response teams must therefore strive for political neutrality. A social scientist could accompany response teams in order to determine local populations' levels of trust towards official structures and to monitor the ways in which politicians may vie to politicize the epidemic in their favor.

Co-ordination is essential, and response teams should build on pre-existing response capacity and work through local officials and partners to ensure that interventions build on the social and cultural resources of the communities they seek to support.

Operational recommendation

» Response teams should designate a member of the logistics or coordination team to fulfil all of the formalities required in order to be approved by the relevant government, customary and community authorities. However, responders should also aim to have relatively unmediated contact with community members once these civilities have been fulfilled.

1.2.2 INFRASTRUCTURE AND MOBILITY

There is a lack of basic infrastructure across Equateur Province including electricity and running water.¹⁷ The province has a road network, but it is in poor condition and only 43 km of it is paved. There are no railways and long-distance travel within the province relies on the river and other waterways. Many areas (e.g. the Ikoko Impenge health area) can only be reached by motorbike or foot. People travel primarily on foot or by bicycle (sometimes up to 500km), or by dugout canoe along tributaries and rivers.

These logistical challenges not only impact response operations but must be taken into consideration when asking communities in more remote villages and forest camps to seek treatment, show up for vaccination campaigns or conduct safe burials.

During the epidemic, the World Food Programme (WFP) set up a helicopter, which would sometimes undertake 6 flights per day to bring supplies from Mbandaka to Bikoro, Itipo and Iboko. Some of the health and administrative officials who participated in this research, lamented the inefficiency of this method, as the helicopter could not transport much weight. Many communities wished that the response team had invested in rehabilitating road infrastructure – an investment which would continue to serve them today.

Local people, especially youth groups, could also have benefitted from the income they would have made from path clearing and road rehabilitation. At the beginning of the Equateur epidemic, groups of young men protested in order to petition for jobs. This was also documented in Nord Kivu.¹⁸

Capacity-building recommendation

» Positively harnessing youth groups to help with logistics including clearing roads and building bridges during the epidemic, would provide the infrastructure necessary to strengthen future preparedness.

1.2.3 SUBSISTENCE AND ECONOMY

The majority of the population relies on agriculture for subsistence and cash crops.¹⁹ People also hunt, fish and gather medicinal and edible plants from the forest, as well as wood for the production of charcoal. In and around the urban centers or larger rural centers, many people are involved in trade and commerce, some of which centers on the bushmeat trade. *See also, 1.3.4 Consumption of game meat.*

Poverty is systemic and entrenched in many parts of rural DRC. The average household lives on less than \$1 per day. People struggle to find the money to pay for health care and school fees to send their children to school. Subsistence farming is hard, and many people suffer from health conditions, such as hernias and back problems, related to the work they do in the fields or when carrying water or firewood. According to the WHO, in 2015, over 22.3% of deaths of women of reproductive age were associated with childbirth.²⁰ Infant mortality is high (nearly 1/10 live births),²¹ and malnutrition is estimated to threaten the lives of 2 million children.²²

Crops harvests can fail, and domestic animals can be wiped out during epidemics. Many hunters report seeing fewer and fewer wild animals in the forest since the bushmeat trade intensified following the civil wars. This means that many people are hungry and undernourished. Beyond these issues related to rural poverty, DRC is facing an economic crisis on a national scale and the cost of living is becoming unmanageable for many households.

Understanding the implications of rural poverty in Equateur Province can help responders understand why Ebola epidemics (and the resources they bring) are often seen as an issue about wealth more than health.

¹⁷ Alcayna-Stevens & Bedford (2018)

¹⁸ Oldenburg (2018).

¹⁹ Alcayna-Stevens & Bedford (2018)

²⁰ WHO (2015).

²¹ World Bank (2017).

²² UNICEF (2015).

1.3 HEALTH, SANITATION AND RISK

The following section summarizes the health context of Equateur Province. It examines the factors which exacerbated the outbreak or led to challenges in the detection and control of the epidemic. It also examines the strengths of DRC's community health networks, which mitigated the epidemic and should be harnessed during any outbreak to ensure that interventions build on the social and cultural resources of the communities they seek to support.

1.3.1 HEALTH SYSTEM & SURVEILLANCE

The province of Equateur has 284 health centers and 18 hospitals for a population of over 2.5 million people. Rural communities may live up to 15km from the nearest health post and 30km from the nearest health center.

There are few qualified doctors in rural areas, and almost all services at health centers and health posts are provided by nurses, midwives and auxiliary health workers, some of whom have never received formal training. Even those with formal training are not necessarily trained to spot diseases of epidemic potential. Nurses who participated in the research at the epicenter of the epidemic (Ikoko Impenge and Itipo) emphasized that they had never heard of Ebola prior to the outbreak and had no idea of the risks of contagion when they began treating the first cases.

A doctor at Bolenge hospital in Mbandaka also suggested that after the epidemic had been declared, some nurses continued to find identifying suspected cases difficult. This is in part because the early symptoms of EVD are similar to some of the most common diseases found in the region, such as malaria and bacterial or parasitic infection of the digestive system: high fever, headache, weakness, muscle pain, nausea, vomiting, diarrhea, weakness. The nurses we encountered in Mbandaka city who had felt more confident in identifying cases were those who had received some training during the 2014 Ebola outbreak in the Boende region, 450km away.

Even when nurses were concerned by patients' symptoms, they lacked the necessary protective equipment to treat suspected cases of EVD. Normally, health centers and health posts receive supplies from international bodies via the general hospital, but they experience frequent shortages and are often almost devoid of medicines, equipment and other materials. They often have limited infection prevention control mechanisms, poor sanitation and hygiene, and electricity shortages. People often travel great distances to

seek adequate healthcare, if they are able, and this increases the spread of an epidemic.

Many doctors and nurses who participated in the research in both rural and urban areas emphasized the difference which could be made in early treatment of cases if they had isolation wards, personal protective equipment (PPE), decontamination materials and incinerators.

They also suggested an immediately accessible epidemic fund. The head of the provisional health division (DPS) told us that provincial epidemic investigation teams often lack the food, fuel and on-hand cash necessary for investigations of suspicious cases in rural areas. This can delay the alert which would lead to an investigation by competent and experienced INRB epidemiology teams, and thus the declaration of an epidemic.

There are two further factors which can lead to delays in national epidemic investigations: (1) many health posts are supported by the church (either Protestant or Catholic) rather than the state, and alerts at the local level are not always taken into consideration by the health zone hospital. This is what happened in Boyeka village in early 2018, which many local people still believe was the origin of the Ebola epidemic; (2) People often seek treatment from many different sources, and epidemics may take some time to become visible to biomedical health practitioners.

The greatest strength in the Congolese health system is the capacity and commitment of community health workers (RECO), community outreach units (CAC) and local health committees (CODESA) – *See also: 2.1.3 Community health workers*. As several of the local health actors interviewed for this research emphasized:

“Epidemics are nothing new”

In order to be effective, response teams must utilize these existing local health structures and actors.

Capacity-building recommendation

» Pilot a variety informal communication and reporting systems for churches, leaders, traditional health practitioners and community health workers to report concerns which have not yet been picked up by state health facilities.

1.3.2 SANITATION

Almost no households in Equateur Province have access to running water and many rural communities struggle to access safe drinking water. Following the epidemic, in September 2018, some villages, such as Moheli, were still receiving drinking water from Oxfam. Many people suffer from chronic parasites and bacterial infections as a result of poor quality drinking water.

Many households also lack adequate pit latrines. Although most people sweep and tidy their yards once or twice per day, domestic animals and small children often defecate nearby during the day, and open-air waste pits are located near houses. While people typically bathe once per day at the nearest river or stream, few people have a habit of washing their hands before eating. Both of these factors exacerbate the transmission of disease.

Operational recommendations

» Children should be encouraged to wash their hands after defecation and before eating when at school and health actors should encourage hand-washing, especially to mothers visiting for routine check-ups or vaccinations.

» People can be encouraged to wash with soap made from ashes, which is affordable and readily available, and projects could be developed to stimulate local soap-making, through which women could also supplement their income.

1.3.3 HEALTH-SEEKING PRACTICES

Care-seeking practices are not static but shift and evolve in response to immediate conditions.²³ Communities are pragmatic and try multiple courses of action in an effort to effect a cure, seeking out different types of care either consecutively or in parallel (including biomedicine, prayer, self-medication and

consulting traditional healers). See also, 2.1.5 *Alternative explanations*.

Whilst rural Congolese are frequently described as seeking alternative care over biomedical treatment, this is often the result of structural barriers that prevent access to biomedical services, including direct and indirect costs associated with consultations and treatment; distance from home to point of service, lack of services (e.g. drug stockouts), or discrimination. These factors are also very important in understanding why patients may choose one health facility over another (for example, while the first cases of EVD were from the health zone

Strengthening health & sanitation systems

» Training materials should be developed on detection of epidemic diseases and case monitoring, to be integrated into the training nurses receive – particularly nurses working in rural, forested areas.

» Efforts should be made to expand the SANRU Rural Health Program (*Projet Santé Rurale*) which works to improve the quality of and access to primary health care and provides free malaria prevention and treatment projects – and to develop similar projects for diarrheal disease.

» Hospitals should have a readily-accessible epidemic fund, which can be used in emergency contexts and to investigate suspicious cases of epidemic proportion.

» Health centers should be stocked with kits containing chlorine and EP for suspicious cases and the protection of health actors, as well as incinerators for hazardous biological waste.¹

» Isolation wards should be built into all health centers to aid investigation of suspicious cases.

» Efforts should be made to ensure access to safe drinking water (wells, natural springs) in all rural villages in DRC in collaboration with the national school and village sanitation programme (*Ecole et Village Assainis*).

» All households should have one well-maintained pit latrine made from affordable, locally-available materials.

²³ Alcayna-Stevens & Bedford (2018)

of Bikoro – Ikoko Impenge village – most had travelled for treatment to nearby Itipo, in the health zone of Iboko, rather than the general hospital of Bikoro, which is where they had been referred but which was much further away.

Traditional medicine includes medicinal herbs and massage (to treat broken bones and fractures). Some of these treatments can be effective in treating certain illnesses, although they can also be dangerous, as dosage can be difficult to estimate, and herbal remedies can be fatal when taken along with biomedical drugs (sometimes expired or of poor quality) bought from pharmacies, markets and informal drug vendors. During the Ebola epidemic, certain communities have attributed the fact that they never became sick to the fact that they took herbal prophylaxis throughout the epidemic.

Caring for sick relatives is very important in Equateur. When a person becomes an in-patient s/he is accompanied by their family members, who feed and care for them. Both the sick and deceased must be washed by their relatives. This is a deeply emotional and cultural practices which cannot be dismissed. However, it does render people susceptible to infection. When preparing the body of a deceased relative for burial, for example, people clean not only the outside of the body, but its cavities, which greatly increases their chances of coming into contact with infected body fluids. This is especially risky with cases of EVD, which is most contagious after death.

Operational recommendation

» **Traditional healing should not be dismissed. Training should be offered to traditional healers and religious leaders about safety, sanitation and how to spot diseases of epidemic potential which may go beyond the care they can offer.**

1.3.4 CONSUMPTION OF GAME MEAT

Experts have still not identified the reservoir species for Ebola, and while they have very strong hypotheses about how ‘zoonotic spillovers’ into human populations occur,²⁴ they do not yet have firm evidence. With their knowledge of forest animals and ecosystems, rural people who use the forest daily can be valuable sources of

information about the emergence of such zoonotic diseases.

Game meat is a valued source of protein throughout the province. It is a source of subsistence or income, as local hunters either consume it with their households/extended families or sell it on a local or regional scale. These two factors, and the fact that most of the time that people eat game meat, they do not become sick, leads many to be resistant to the idea that it could be a source of Ebola.

Messages which prohibit or stigmatize the eating or selling of game meat can be harmful to people’s health and income, because they may end up reducing their protein intake and unable to make money selling meat – they may have no alternative source of income. This is one of the reasons that some people demand work from response teams as ‘compensation.’

Demonizing bushmeat can also have the effect of stigmatizing hunters, many of whom are from Twa communities and already marginalized and suffering from extreme poverty. *See also, 1.3.1 Ethnic minorities.*

During the epidemic, the Health Minister, Oly Ilunga, emphasized that bushmeat hunting, trade and consumption were not prohibited, but that people were strongly discouraged from eating animals found dead or dying in the forest. While Dr Ilunga’s statements were clear, some of the information and training workshops nonetheless suggested an outright ban on bushmeat consumption, and even dissuaded people from eating forest fruits.²⁵

Operational recommendation

» **As in previous outbreaks, a total ban on wildlife consumption is often counterproductive, raises suspicions and is likely to be rejected by the local population.²⁶ The message should be about animals found dead or dying in the forest.**

Capacity-building recommendation

» **Veterinarians and epidemiologists specializing in zoonotic disease and a ‘One Health’ approach should be deployed in rural regions to monitor the health of wild and domestic animal populations.**

²⁴ Leroy et al (2009).

²⁵ Duda (2018).

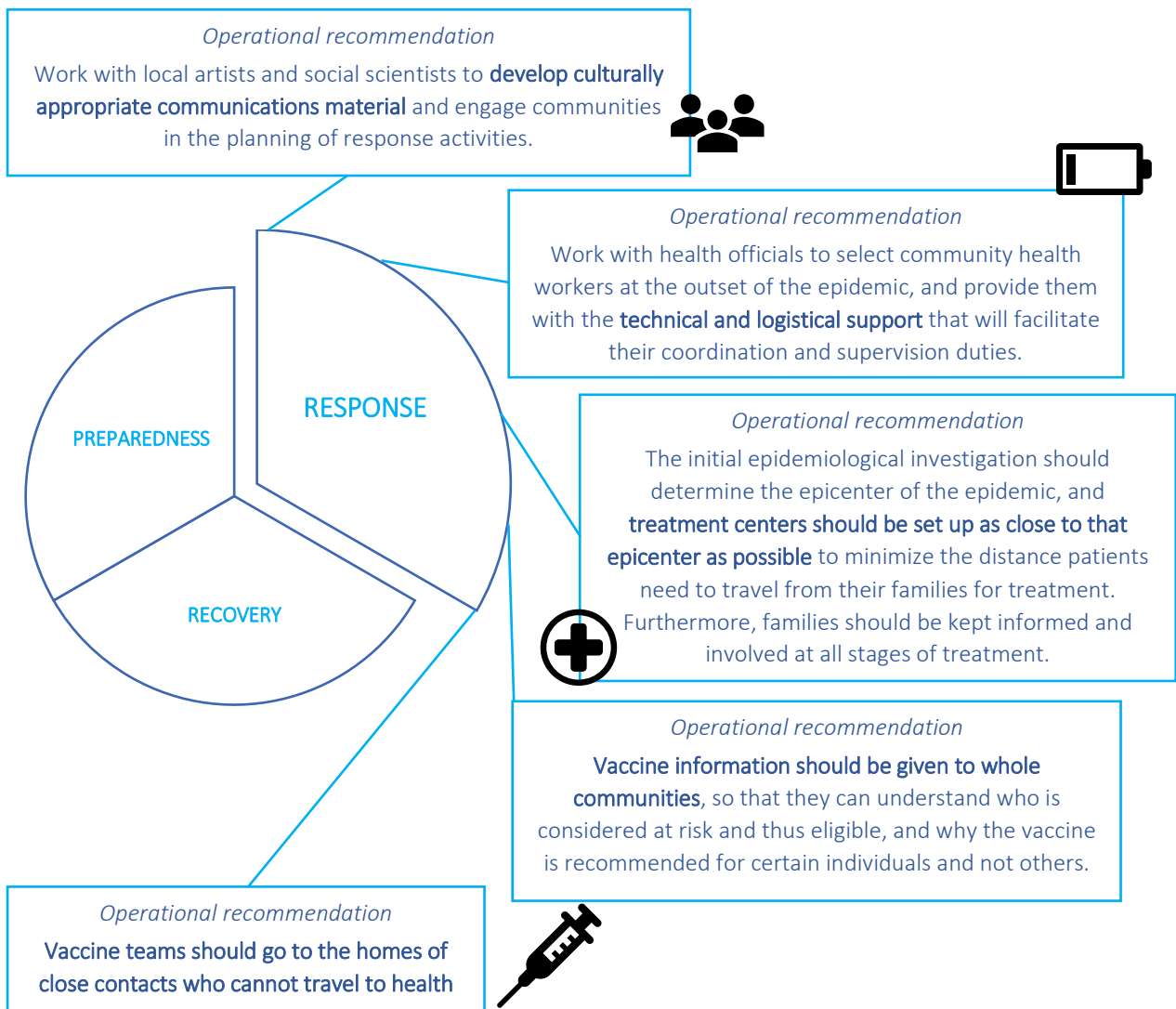
²⁶ Bonwitt et al (2018).

PART II | RESPONSE



PLANNING FOR POST-EBOLA: RESPONSE

An effective epidemic response requires coordination on the part of epidemiologists, clinicians, logisticians and communications experts. Epidemiologists are involved in outbreak investigation, surveillance and contact tracing. Clinicians are involved in vaccination, case management, and in the management of safe and dignified burials. Communications experts are integrated into the other pillars and facilitate two-way communication between responders and communities. The technical teams must be supported by local political, administrative and public health authorities, which make decisions on infrastructure, regulations, vaccinations, and so on, based on advice from the coordinating team. The coordinating team is made up of representatives from the technical subgroups, logistics and administrative personnel, and headed by the representative of the Ministry of Public Health. This section of the report provides detail on areas of the response which could have been more coordinated and effective during the 2018 Equateur outbreak.



2. RESPONSE

2.1 RISK COMMUNICATION AND COMMUNITY ENGAGEMENT

The following section summarizes the communication and community engagement work which is the most important aspect of any epidemic response: without the support and participation of the community, responses are doomed to failure. UNICEF is committed to recruiting local mobilisers, thereby enabling the response to have access to local knowledge and a deep understanding of the context. Two-way communication is essential to the establishment of trust and to finding effective solutions. It is particularly important because people's attitudes and priorities shift as a product of their relationship with the disease and the response itself.²⁷ Communication media should therefore be constantly rethought and redesigned.

2.1.1 COMMUNITY ENGAGEMENT

Community engagement (CE) is the stimulation of community dialogue platforms (urban, rural, media, other) and is a process not an event. CE aims to support community leaders and assure that decisions are made with a participatory approach where voices of women, youth and the marginalized are heard.

The objective of community engagement activities is to reach as many people as possible. In Mbandaka, workshops were organized for health actors, and taxi and bicycle chauffeurs. These efforts are to be commended. The bicycle and taxi chauffeurs were able to reach a wide cross-section of the population. However, we identified three other groups which could have benefitted from engagement and risk education: religious leaders, customary leaders (*see also 2.1.4: Local leaders*) and women's associations (*see also 1.1.3: Gender*).

Community engagement activities should be made as participatory as possible. This means that they should be presented in a language which can be understood by all participants, that people should have numerous opportunities to choose groups within which they feel comfortable participating, e.g. some activities aimed particularly at ethnic minorities or women.

When people feel that they lack information and decision-making power frustrations can quickly develop. Communities should be engaged in the planning of response activities and consulted as these activities develop and change. As well as fostering active participation, this

practice can provide the response with operationally useful information.

Different modes of community engagement that tap into a variety of local platforms should be employed strategically and should be evaluated so that limited resources can be channeled to have the greatest impact, while targeting a range of different groups: e.g. health workers, women's associations, taxi and bicycle drivers, customs agents, religious leaders, customary leaders, etc.

2.1.2 COMMUNICATING RISK

Risk communication refers to the exchange of life-saving information during times of threat and danger. When confronted with accelerating community deaths, people are more likely to incorporate health information, provided they acquire it through local networks.²⁸ UNICEF therefore trains community health workers and local leaders in risk communication.

Action-based workshops that use 'edutainment' methods and role-play have been reported to be well received with attendees displaying a higher-level of sustained engagement.²⁹ Rather than simply repeating basic messages and offering instructions, explanations must be offered about the rationale behind the behaviors (e.g. hand-washing, SDB) being proposed.

It is important to be aware that people will often expect compensation for the time they take to attend activities and workshops, in the form of food on the day, and money 'for transport'. During the outbreak, tensions erupted when it

²⁷ Ripoll et al (2018).

²⁸ Abramowitz et al (2017).

²⁹ Bedford (2018a).

was discovered that the response was paying the owners of taxi motorcycles and not the taximen themselves for their risk communication activities.³⁰ Participants of community engagement activities and those undertaking RCCE should be fairly paid or compensated – research should be conducted to make sure that it is those conducting the work, and not mediators who are paid for this activity.

Meaningful community dialogue which facilitates the two-way exchange of information should be encouraged. Different modes of community engagement that tap into a variety of local platforms should be employed strategically and should be evaluated so that limited resources can be channeled to have the greatest impact, while targeting a range of different groups: e.g. health workers, women’s associations, taxi and bicycle drivers, customs agents, religious leaders, customary leaders, etc.

Operational recommendation

» **Communication teams should inform different populations about all aspects of the response, so that certain elements (e.g. SDBs, vaccination, ETCs) don’t remain mysterious to the broader community.**

2.1.3 COMMUNITY HEALTH WORKERS

As respected members of the community, community health workers (RECO) were invaluable in RCCE activities. Given their experience, they were able to begin activities right away, doing from ‘door to door’ and promoting open discussions and providing community feedback for response teams. RECO activities were coordinated through the community outreach units (CAC).

However, they often lacked the equipment and support (e.g. bicycles or motorbikes, fuel, torches,

LOCAL CAPACITY

Ministry of Public Health (MPH) - Develops health policies and standards and coordinates technical and financial partners, such as donors and NGOs at the national level.

National Institute of Biomedical Research (*Institut National de Recherche Biomédicale* or INRB) – Established in 1984, it provides laboratories for experts working on haemorrhagic fevers (Marburg and Ebola) and other tropical diseases.

Provincial health division (DPS) – Collects, analyzes, and interprets health data from the health zones. It transmits information to administrative provincial authorities as well as the MPH.

Health area development committee (CODESA) – Includes members from important social groups, local networks and opinion leaders, and social service partners, and works at the level of the health area, each of which contains approximately one health center. The CODESA participates in health activity planning, management, and monitoring; conducts community mobilization; receives reports from the CAC; and meets monthly with health center staff to analyze results and resolve issues.

Community health workers (*relais communautaire* or RECO) - RECOs are volunteers who have promoted and provided health interventions in communities for many years. RECOs are volunteers who deliver a minimum package of activities related to reproductive, maternal, newborn, and child health (RMNCH), including integrated community case management for malaria, diarrhea, and respiratory diseases; nutrition; WASH; HIV and AIDS; and disease prevention. RECOs conduct home visits, household mapping, referrals, monitoring, and community-based surveillance. They have three-year renewable contracts with local authorities but can be replaced before the end of the contract if the community is unsatisfied with their performance.

Community outreach units (*Cellule d’Animation Communautaire* or CAC) - Led by an elected local leader (the community animator, or ‘AC’), they comprise influential elected individuals from that locality, including RECO. The CAC meets monthly and reports to the CODESA. It coordinates village development activities; promotes healthy behaviors; coordinates RECO activities, including delivery of the minimum health package; supports distribution of health products; conducts community mapping and monitoring; and manages community care sites.

³⁰ More detail on the risk communication activities of taxi motorcycles can be found in Kemba (2018).

watches, phone credit) necessary to undertake their work. Several met with resistance early in the epidemic and would have appreciated official uniforms which they could have used to legitimate the messages they were giving people.

The RECO who participated in this research emphasized the quality of the WHO/UNICEF training they received through Oxfam, IFRC and CARITAS. However, representatives of CAC and community health committees (CODESA) felt that WHO workshops would have been more effective and wide-reaching if they had been conducted in collaboration with the CAC and CODESA, as UNICEF training workshops were.

Many RECO who participated in the research were frustrated at the discrepancies in pay – and late payments – between different organizations (i.e. UNICEF and WHO). Many RECO argued that just because they are normally volunteers, does not mean they should be paid so little (\$2 per day for some) to do work which they found dangerous and stigmatizing. They were particularly frustrated by this when word circulated that certain international responders were receiving a per diem of \$300 per day, while working in air-conditioned rooms in the coordination offices.

Operational recommendations

» **Provide RECO with logistical support (e.g. bicycles, phone credit, watches, torches).**

» **Make sure that RECO are being paid fairly, consistently and on-time. Psycho-social experts should be assigned to support RECO who may be stigmatized or encounter resistance.**

2.1.4 LOCAL LEADERS

The engagement of trusted local authorities and community leaders is essential in order to stem misinformation and fear, to encourage people to report symptoms, to help minimize social stigmatization, and to facilitate exchange between the response and communities. However, in rural Congolese communities, there is rarely one community leader, and a range of leaders should be targeted.

The first of these are customary leaders – village chiefs or ‘groupement’ chiefs and village elders. Customary leaders, elders and traditional healers

have many traditional ways of stimulating community support or adherence.

The second are religious leaders. They are trusted members of the community who people turn to in times of sickness and distress, and their word carries weight. They also have the attention of large numbers of the population at least once a week, and sometimes every morning or evening. As one pastor explained:

“If the message has not been relayed by a religious leader, then you might as well say the message has not been received”

Most rural Congolese are Christian (even as they simultaneously hold non-Christian beliefs). However, there are a wide variety of churches. During the epidemic, the Catholic Church was very active in RCCE and suspended sacraments.

The Protestant Church (federated under the *Eglise de Christ du Congo*) also participated in RCCE and attempted to support affected protestant communities. However, they often lacked the support of CARITAS, a formal structure of the Catholic Church providing logistics, healthcare and sustainable development, and a local partner of UNICEF. We were told by two Protestant pastors that CARITAS supports Catholic churches and health clinics more than Protestant ones, even with epidemic funds. It is essential that CARITAS distribute resources supplied by partners like UNICEF fairly, regardless of religious denomination.

The response was not successful in engaging the majority of Pentecostal churches, some of which were actively opposed to the response’s Ebola narrative and RCCE efforts. Response teams should try to engage the leaders of Pentecostal churches into the response by reaching out to them directly and through adherents who are themselves health actors.

It is important to remain aware that recruitment of traditional leaders runs the risk of ignoring the needs and voices of marginalized populations.³¹ See also: 1.1.2 *Ethnic minorities*; 1.1.3 *Gender*. Trusted community leaders do not always coincide with self-appointed leaders, and social scientists should attempt to identify important

³¹ Gillespie, Obregon et al. (2016).

local leaders through discussions with the community, while attempting also to look for power struggles or conflicts.

Operational recommendation

» **Pastors should be trained in risk communication and encouraged to cascade information to their congregations. As should church-based community mobilizers. Religious leaders would also benefit from psycho-social training and could be encouraged to organize support groups in which people could voice their anxieties about the epidemic and the response.**

2.1.5 ALTERNATIVE EXPLANATIONS

At the onset of the epidemic, there were many alternative explanations for the escalating community deaths. Many of these centered on accusations of witchcraft connected to land disputes, to punishment by ancestors or angered traditional healers, or to jealousy or revenge.³²

The reason that these stories continued to persist throughout the epidemic, and continue to do so even now, when most people believe that the deaths were connected to the Ebola virus, is that even when it is accepted that an individual has a biomedical disease (e.g. tuberculosis), family members will still search for the reason *why* that individual became sick with that disease.

Other stories also abound concerning, not the origins of the outbreak, but the reason for which it continued to spread to other villages. Some people believed that foreign and national response teams had used the spate of community deaths to come and infect people with Ebola to make money during the response and through the deployment of the vaccine. This is connected to a fear and suspicion held by many people that biomedical and traditional healers have the power to kill as well as the power to cure.

Communication teams must make it their priority to tackle misinformation at every level of community engagement, by providing clear, consistent information and listening to concerns. In official terminology in the North Kivu outbreak, the terms ‘alternative explanations’ and ‘circulating stories’ are already being preferentially deployed over ‘rumor tracking’, which suggests negative and false information.

It is important to understand the factors which lead to alternative explanations – they are not simply the product of ‘ignorance,’ but are often based on past experience, on particular local histories and politics and on very real fears.

Communication teams should understand the underlying basis and stakes of alternative explanations in order to integrate counter-arguments into their messaging and community engagement activities.

2.1.6 USING MEDIA

Language and literacy are important factors when considering the use of media in RCCE. Several local community animators told us that people in the villages of Bikoro and Iboko health zones could not understand the health education posters and flyers due to high levels of illiteracy.

Furthermore, one Mbandaka-based sociologist informed us that people found the imaging confusing – e.g. the man wrapped in a blanket did not make them think of fever, but rather that a cure for Ebola was to wrap up in warm clothes.

The sociologist emphasized that oral communication is much more effective in rural Congolese villages than visual communication. This was echoed by community members who emphasized the importance of radio and the use of megaphones. Better than megaphones, according to RECO, however, was the ‘door to door’ (*porte a porte*) method, in which they visited each family in order to spend time explaining the RCCE messages to them in person.

Communications teams should prioritize oral communication in the form of announcements, information sessions, radio programs and ‘door by door’ communication in order to meet the delivery needs of rural populations. In North Kivu, advances are also being made with music, social media platforms and mobile phone messaging.³³

Operational recommendation

» **Communications teams should work with local artists and social scientists to create risk communication media, rather than bringing pre-made posters and flyers.**

³² More detail is provided in Duda (2018).

³³ Bedford (2018b).

2.2 CONTACT TRACING & VACCINATION

This section outlines how response teams successfully ‘broke the transmission chain’ through surveillance, contact tracing and the first vaccine (rVSV-ZEBOV) deployment during an active Ebola epidemic. During interviews, several local doctors suggested that the epidemic would have been ‘a catastrophe’ without the vaccine. However, the section also examines the short-comings of the vaccine deployment in Equateur, and the ways in which future campaigns could be improved.

2.2.1 CONTACT TRACING

Contact tracing relies on identifying those who have had close contact with an infected person, as well as contacts of those contacts, so that they can be monitored for symptoms of the disease. Some of these people may be incubating the disease, and the purpose of contact tracing is to locate them so that they can be vaccinated and monitored.

RECO were as invaluable in tracing contacts and monitoring contacts as they were in risk communication activities. Understanding local family structures and how this translates into responsibilities for care and burial is crucial to understanding mobility and being able to locate contacts. This is where RECO’s experience and embeddedness within communities becomes indispensable.

These RECO often lacked the equipment and support necessary to undertake and coordinate their work – especially when contacts were hidden in difficult-to-access forest or river camps necessitating ‘expeditionary surveillance.’ They were also frustrated at the discrepancies in pay – and late payments – and in organization between different organizations (i.e. UNICEF and WHO).

Given their daily interactions with contacts, they lamented that they were not offered full personal protective equipment (PPE). This equipment was determined by epidemiologists to be unnecessary for RECO, if this is the case then they require further training in order to be reassured of this.

Several presidents of the local health committees (CODESA), themselves RECO, argued that many RECO were frustrated in their efforts to complete their tasks because they could not read the forms they were asked to fill out. They suggested that in future epidemics, organizations coordinate their efforts and ask CODESA presidents to suggest suitable (literate and reliable) RECO.

Some community animators (AC) pointed to the ways they coordinate other epidemic (e.g.

cholera) surveillance, with weekly schedules, so that they can easily localize RECO. They noted that the Ebola epidemic was more pressurized and chaotic but suggested that being more involved in the initial selection and coordination of RECO would have made surveillance run more smoothly and effectively.

Several of the AC we interviewed who had supervised RECO, lamented the different forms used by UNICEF and WHO, which made it more complicated for them to synthesize data and transmit it in their own reports. In order to complete this painstaking work each day, they would have appreciated access to a computer and printer. They would also have appreciated compilation forms, where they could rapidly synthesize the data provided by RECO. They also noted that sometimes they were not provided with enough forms and could have benefitted from access to a photocopier in order to provide for all the RECO under their supervision.

Some RECO suggested that they had not been taught how to fill out the forms correctly, and that in some cases they were not paid when forms had mistakes, despite the fact that they had worked that day. Once again, this may have been avoided if AC and presidents of CODESA had coordinated the deployment of RECO from the start.

Operational recommendations

- » Provide RECO with logistical support (e.g. bicycles, phone credit, watches, torches).
- » Involve AC and CODESA in the selection and coordination of RECO right from the start – work with them in order to homogenize forms, create synthesis forms and schedule RECO activities. Make efforts to give RECO supervisors access to computers and photocopiers.

2.2.2 MONITORING

Once contacts have been established and located, they are interviewed and checked for symptoms (particularly temperature). If the contact is found

to be symptomatic, they should be transported to an Ebola treatment center and tested there. Testing the patient while they are still in the community is to be avoided, as it delays moving them to a safer location.

All close contacts were monitored for 21 days following their last known exposure to a case. They were monitored on a daily basis and their temperature taken.

Contacts were also encouraged not to leave their houses (and thus limited in their economic activities). Provision of food was the primary concern for people when committing to isolation, and they were therefore given supplementary food (rice, beans, oil) by UNICEF and WFP.

RECO worked in close collaboration with the psycho-social experts, who sought to reduce stigmatization of those affected (including the families of contacts) by counselling those affected and educating and reassuring families and neighbors. Many families cited this distribution as one of the factors which made them collaborate with the response.

2.2.3 PERCEPTIONS OF THE VACCINE

Frontline health workers were vaccinated, followed by a ‘ring vaccination’ method which targeted contacts of patients and contacts of contacts. Communication around the vaccine is crucial as negative community perceptions and understandings of why some people are vaccinated and others not augments social risks associated with distrust, suspicion and stigmatization.

Despite concerns that communities may be resistant to it, however, the ring vaccination campaign was largely successful.

Nonetheless, there were, and continue to be, certain negative perceptions surrounding it. Some of these include rumors that Ebola was re-introduced to the DRC to enable the experimental rVSV-ZEBOV vaccine to be trialed. Other fears were that the vaccine would kill or sterilize those who received it, or that it would give them Ebola. This fear was especially prevalent among Twa communities, and was best countered by RECO and APS who were themselves PA. *See also 1.1.2: Ethnic minorities.*

There was some concern about ‘resistance’ to the vaccine among Twa communities.³⁴ Adherents of certain evangelical and revivalist movements also appear to have been opposed.

While overall people were satisfied with the follow-up exams and treatment they received for side-effects, the initial fear, and a lingering concern, are very real. Several of the people who participated in the research continued to experience pain in their arms at the site of the injection several months later. In one village, several people reported feeling nauseous in the first 2-3 days, and then feeling incredibly hungry – a hunger which was still with them to this day. Further research must be conducted to determine the long-term physical effects of the vaccine, as well as the ways in which it comes to symbolize larger grievances with the response.

We also came across several villages where people did not feel that they had given their informed consent prior to the vaccination. There appear to have been discrepancies in the deployment of the vaccine, with some people having read and signed consent forms before their inoculation, and others being presented with the forms only after they had been inoculated. People also lamented the fact that consent forms were written in French, even though many people either do not speak the language or cannot read. This was a source of particular concern for those who said that they had not even realized that the vaccine was experimental until after it had been administered.

Several of the people who participated in the research felt that they had been used as test subjects for pharmaceutical companies which would now make billions of dollars selling the vaccines:

“They will sell that vaccine for billions. It was tested on us, but we will not benefit.”

Education campaigns need to be sensitive to fears which are not purely about ignorance, but about a real affective and visceral feeling of fear – communities cannot simply be given information, they must be given reassurance and allowed to voice their fears and concerns in order to progressively develop communications around

³⁴ Anoko & Falero (2018).

the vaccine, including in the months following vaccination. *See also: 3.1.5 Embezzlement & unfulfilled promises.*

Even if they are not contacts, it may be beneficial to publicly vaccinate influential community leaders and administrators who volunteer for the vaccine in order to reassure the broader community.

Operational recommendations

» Rumors about the vaccine can be combatted most effectively if education, information and reassurance is given to whole communities, and not simply to those within the ring, so they can understand why the vaccine is recommended for certain community members and not others.

2.2.4 SIDE EFFECTS OF THE VACCINE

There were also issues around the communication of risk to pregnant women. Until the ethics committee came to its decision on the protocol for pregnant and breastfeeding women (i.e. during the first few days of the campaign), these women were vaccinated – apparently without any supplemental information on potential health risks. People who participated in the research described one woman who had a miscarriage afterwards, and one woman who had a still birth. We also heard reports of other women who experienced bleeding after the vaccine. These women blame the vaccine and demand ‘justice’ and compensation for their loss.

Protocols for obtaining consent should always be followed, and information given in a language and format which patients can easily understand. Any populations at higher risk (e.g. pregnant women) should have this clearly explained to them at some length before receiving the vaccine.

Operational recommendation

» Aftercare should be provided to women who lost a child after being vaccinated.

2.2.5 VACCINE: BARRIERS TO ACCESS

The vaccine was so popular that many of the people who participated in the research said that after an initial fear and resistance, they had sought out the vaccine only to be denied. In most cases, this was because they were outside the ring. However, many people had understood that

the vaccine had simply ‘run out.’ This misunderstanding suggests that more could be done to inform broader communities about the role of the vaccine campaign.

In one village, we were told that once contacts and health actors had been vaccinated, the vaccine was opened up to village leaders (such as religious leaders and elders). We could not verify this information, but if it is true, then it may have contributed to understandings that the vaccines simply ‘ran out.’

More worryingly, however, we also found several cases of close contacts who had not been vaccinated despite the fact that they would have liked to be. Some were elderly or sick people who had not been able to make the journey from their village or homestead to the health center where the vaccines were being administered. Others were widows who, despite being in direct contact with deceased husbands, were in a period of mourning and seclusion which did not permit them to leave their homes to travel to the health centers. Other contacts said that they had simply not been informed about the vaccine campaign.

Health actors with whom we spoke compared the vaccine campaign unfavorably with their own routine vaccine campaigns, in which they go from door to door to make sure that all children are vaccinated. They argued that restricting the vaccine teams exclusively to health centers (some up to 10km from contacts’ homes) limited the number of people eligible for the vaccine who could actually attend the vaccination. Health actors also pointed to the fact that some people were temporarily absent in hunting, fishing or gathering camps deep in the forest, and that the campaign should have passed through again one or two weeks later in order to reach those people who had returned from the forest.

Vaccination protocol should consider the benefits of vaccinating community health workers, hygienists and burial teams. If this is determined to be unnecessary, then these people should have the reasons for this decision clearly explained to them.

Operational recommendation

» Vaccine teams should consider visiting villages twice to reach people who were temporarily absent, and actively going to the homes of people who cannot travel to health centers but are nonetheless close contacts.

2.3 TREATMENT OF THE SICK AND DECEASED

This section outlines the significant improvements which response teams have made in caring for the sick and the deceased since the first Ebola epidemic in 1976. Even during the West Africa crisis, 2–4 years ago, ETCs were often thought of as ‘death camps’ – by the end of the Ebola epidemic in Equateur, however, they were being referred to as ‘paradise-like.’ Nonetheless, improvements can still be made in several aspects of care, especially through community participation in safe and dignified burials.

2.3.1 TAKING BIOLOGICAL SAMPLES

One of the strongest cases of resistance encountered by response teams was against the taking of biological samples from suspected cases (sick patients or the deceased).

There are two primary reasons for this resistance: (1) people fear that in taking samples, response teams may give them Ebola or in some other way harm them; (2) early in the epidemic, being diagnosed with Ebola, or having a deceased family member diagnosed with Ebola post-mortem, was a source of shame and stigma.

It is from the practice of taking blood samples that response teams acquire the name of ‘vampires’ or ‘blood-suckers’ (*suceurs de sang* in French). It is often rumored that they take such samples in order to bewitch a patient or else sell his or her blood or body parts. It is particularly difficult to convince family members to allow samples to be taken from a deceased relative, as by that point, nothing more can be done to treat or save them.

To get around this early resistance, several health actors admitted to telling patients that they would have a routine exam of blood, urine and stool samples for another disease, and then secretly testing their sample for Ebola. This clearly raises ethical concerns around consent, but it was framed by health actors as the best way to minimize the stigma and fear associated with being tested for Ebola.

One of the most impactful issues, in the long term, concerns the fact that patients are seldom informed about a negative result. This leaves many people wondering whether they or their family members had EVD. Given the significant food and monetary assistance Ebola survivors have received, this has led some people, particularly in the village of Boyeka (which some believe may have been the source of the Ebola outbreak as far back as January 2018), to make claims on the government and response, demanding that they receive the same level of

support and compensation for their losses. The authorities, however, refuse to do so, saying that an epidemiological team tested certain cases in Boyeka and found no evidence of Ebola. However, the affected community has never officially been informed.

Response teams must work closely with community health workers in order to provide families with accurate information and allay their fears. The first people to speak with affected families should be communications and psycho-social experts, in order to minimize the attention and shame which can accompany the appearance of a biomedical team.

Furthermore, it is imperative that individuals, families and communities tested for Ebola are informed, in a timely manner, if their results are negative.

2.3.2 PERCEPTIONS OF ETCs

Ebola Treatment Centers (ETCs) are often established alongside functioning health facilities. MSF set up their initial ETC close to Bikoro general hospital. However, given that people had travelled from villages in that health zone to a closer hospital in Itipo village, many cases were being diagnosed more than 40km from the MSF ETC, requiring patients to travel (or be transported) far from their families for treatment. This greatly exacerbated resistance at the start of the epidemic.

People often find Personal Protective Equipment (PPE) frightening, saying that doctors look like ‘monsters’ or ‘aliens.’ This can be minimized if suits are taken on and off in public, and by making sure that doctors never arrive in a village already wearing them.

As the epidemic progressed, people became less afraid of ETC. This was due to two primary factors: (1) the opening of an ALIMA ETC in Itipo which meant that patients did not have to travel far from home; (2) the reintegration of Ebola survivors who had been successfully treated in

ETCs. Survivors and their testimonies can demystify ETCs, and they often play an important role in bringing trust and hope to communities about patient care in the ETCs, and proving, through their own experience, that with treatment and care, people can survive.

In the West Africa outbreak, community members and leaders were given tours of ETC 'green zones'. This was not the case in Equateur, but several people who participated in the research had heard positive stories about ETCs both from survivors and from community members working as hygienists, nurses or on construction work around the ETCs.

The importance of family care and of not being isolated should not be underestimated. Typically, when rural people spend time in hospital, they are accompanied by their family, who become their 'guardians' (*garde malade* in French). The role of such guardians is not simply to provide solidarity and companionship through the biomedical process, but also to provide meals for the patient (food is not provided at hospital), giving additional personal care, negotiating their treatment (including payment) and advocating with health workers on their behalf.

Some of the people who spoke about early experience with ETC, told of frightening and confusing encounters in which they were not kept informed about the status of their family member and about the kind of treatment they were receiving.

The response must negotiate a delicate balance between encouraging patients to seek treatment at an ETC, where they can be monitored and isolated, and recognizing that patients are there voluntarily. This is especially complex when patients are too weak to express their wishes and when families must make decisions on their behalf. The two patients who were taken from the ETC in Mbandaka on 22 May, sought alternative treatment at church prayer groups. The family told us that they were then taken back to the ETC by police and soldiers by force.

However, towards the end of the outbreak, patients were actively seeking out treatment at the ALIMA ETC in Itipo. While no confirmed Ebola cases were treated at this ETC, several health workers and other community members described it as 'like paradise,' with good food,

clean sheets, air conditioning, music playing, toys for children to play with. They also appreciated the ALIMA Biosecure Emergency Care Units (CUBE) because they were able to see family members throughout their treatment and wave to them from a distance.

In order to demystify ETCs, response teams should introduce people to hazmat suits and body bags during risk communication activities and survivors (including the national survivors' association, ANVE) should be employed in RCCE activities and on radio programs. Some survivors can also provide help within ETCs themselves, given that they are no longer at risk of Ebola contamination.

Engaging religious leaders to hold prayer sessions in proximity to the sick (but behind protective barriers) in ETCs, may also provide psychosocial support and discourage patients from absconding to seek alternative treatment.

Operational recommendations

» **The initial epidemiological investigation should determine the epicenter of the epidemic, and the ETC should be set up as close to that epicenter as possible to minimize the distance patients need to travel from their families for treatment.**

» **Patients cannot be treated as atomized individuals. Their families must be kept informed and involved at all stages of treatment.**

2.3.3 SAFE AND DIGNIFIED BURIALS

Ebola has been called a 'disease of social intimacy' because it disproportionately affects those meeting their social responsibilities to care for their loved ones, including healers and doctors, who are highly respected people in their communities.³⁵

While much is often made of the role of health actors as agents in 'super-spreading events', the Itipo nurse who contaminated several other people, did so not through medical practice, but because he was a respected and beloved member of the community, whose body was carried by many and whose funeral was attended by several hundred people. This example serves to illustrate that safe burials are one of the most important

³⁵ Richards et al (2015).

elements in breaking the transmission chain of EVD.

Safe, securitized burials are also an important site of resistance. This has been reported in previous outbreaks and centers on the fact that deceased Ebola patients have often been buried by response teams without a funeral or coffin and without the presence of family members. It is well documented that having no proof of death and not being able to bury a relative in an acceptable manner, compounds the distress experienced by communities and fuels suspicions that people are being murdered and their organs and body parts sold by response teams. This can have a continuing and devastating impact on the everyday life and long-term mental health of affected communities.

It is for this reason that protocol now specifies use of the term 'safe and *dignified* burial.' Dignified means that burials should be appropriate for the cultural context and take account of the individual preferences of families on the timing and location of the burial, and on important ritual and aesthetic elements, including a coffin, prayers and the possibility for mourners to see the deceased's face. Viewing the body and face of the deceased is often of crucial importance, both as a way for family and friends to pay their respects to the deceased, and to provide visual confirmation of death and of an unutilized corpse.

Response teams face numerous logistical challenges, particularly in the case of 'community deaths.' People told us that they waited hours or days for the Croix Rouge burial team to arrive, and ended up burying relatives themselves and without protection. We also heard stories from the early stages of the epidemic where people heard of a relative's death through unofficial channels before being informed by a health official. The timely announcement of death and undertaking of an SDB should be priorities for response teams.

The critical importance of involving communities in the adjustment of SDB protocols to ensure they are locally appropriate and acceptable, keeping family members well informed and facilitating their engagement with SDB practices, and providing sustained psychosocial support, cannot be over-emphasized.

SDB should be a priority right from the start of the response and people should not be left waiting for a burial team for long when there is a community death – RECO can be used to monitor the sick and to inform teams when a death appears imminent.

Efforts need to be made in risk communication and with psycho-social experts to inform communities about the importance of SDB and to gather feedback on appropriate SDB for the cultural context. Focus groups can help response teams prepare appropriate materials and resources, but SDB should always be conducted according to guidance from the bereaved family itself.

It is important that families give prior consent for an SDB and that they are not coerced by military, police or health authorities. Efforts should be made to assure that SDB teams always include one psycho-social expert. The response may also consider including religious or customary leaders, who would benefit from the training and information and could help to put bereaved families at ease.

Operational recommendation

» SDB teams should provide coffins and a small contribution for the funerary rituals of Ebola victims and cloth to line the coffin.

2.3.4 FREE HEALTH CARE

Free health care during and after the epidemic has helped to strengthen and rebuild people's trust in health structures and practitioners and has led to early reporting and presentation of signs and symptoms, thus facilitating surveillance efforts. It is one of the most widely praised public health strategies of the intervention.

However, it is not without its challenges. At first, people were very suspicious, and some people avoided the health centers, fearing that free medications were people used to give people Ebola. These fears had been reduced by RCCE and when people treated did not catch EVD. However, people also found the infrared thermometers frightening, because they resemble guns and do not need to touch a person in order to read their temperature, but do so, as if 'by witchcraft' (*kindoki* in Lingala).

More importantly, however, free health care has put the whole rural health system under strain. This is not simply because they are understaffed and experiencing high demand – hundreds of patients per day according to one of the nurses who participated in the research. It is also because many rural nurses do not receive a regular state salary, or any salary at all (many lack a social security number and there are numerous obstacles to transferring money to rural areas with no banks for hundreds of miles). These nurses make a living by charging for consultations, or by making a small profit on the sale of medicines. Nurses (who often work in villages which are not their own, and therefore cannot rely on family support networks) use the money they earn through consultations to buy agricultural produce. As one nurse explained:

“The health centre is my field; if I cannot harvest from it, I will starve.”

While rural health actors are supposed to receive support and compensation for this lost income, in practice, many of those who participated in the research said that they had received nothing. While some were receiving gifts from the people they were treating, many of the nurses we spoke with were struggling to support themselves, let alone afford their children’s school fees. Some said that this was leading certain members of the community to mock and stigmatize them, while

their own family members continued to ostracize them for fear of catching EVD.

Some doctors in Mbandaka accused rural nurses of continuing to charge people for health services. We were unable to verify these claims. However, some of the nurses who participated in the research said that they were charging people for medicines which had run out and were now only available in the nurses’ own pre-Ebola stockpiles (which they had bought with their own money).

The depletion of medications was the only universal criticism which we heard about free health care. Nurses told us that many of the most commonly used medications had run out and were not being restocked, while other, less useful medications were being replenished but left unused. Nurses would have preferred to order in those medications they needed most and should be given the possibility to offer feedback on the medications and supplied they require and to place orders.

Psycho-social experts should be assigned to support health actors who may be stigmatized in their own families and within the communities they treat.

Operational recommendation

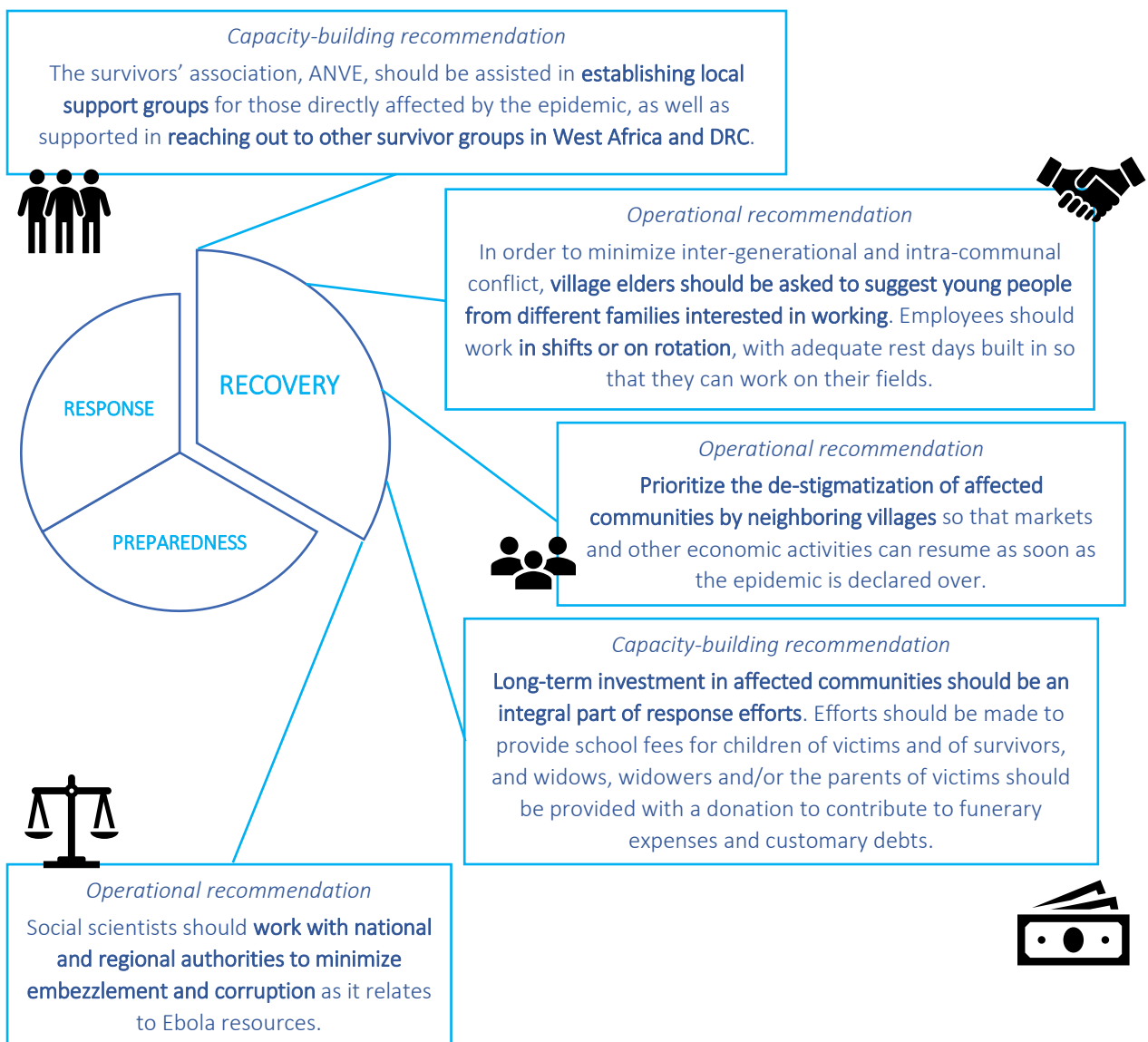
» **Free health care must imperatively be accompanied by the full and timely payment of rural health actors and structures put in place to check and monitor this payment.**

PART III | RECOVERY



PLANNING FOR POST-EBOLA: RECOVERY

For an Ebola outbreak to be officially declared over, two incubation periods (a total of 42 days) must pass without any confirmed cases. Traditionally, recovery efforts focus on governments driving the safe reactivation of essential health services and tackling pre-existing health system constraints that contributed to delayed detection and early spread of the virus. Immediate recovery efforts should lay the foundations for a stronger, more resilient health system, and thus feed back into preparedness. However, the research conducted in preparation for this report has suggested that recovery should be conceptualized beyond the improvement of health services and should encompass the broader psychosocial and economic impacts of the epidemic. This section of the report provides detail on the challenges with which communities and individuals affected by the 2018 Equateur outbreak continue to struggle, and to suggest an approach to Ebola epidemics which would plan for life ‘post-Ebola’ at each stage of the response.



3. RECOVERY

3.1 ECONOMIC IMPACTS

Response teams must consider from the outset the kinds of enduring impacts their presence could have on local economies. This section outlines the significant economic impacts that an Ebola epidemic has on survivors, their families, the families of victims, and broader communities. It also examines the unintended economic impacts that the Ebola response teams have on local economies and on the economic conditions of individual families.

3.1.1 COST OF LIVING

Itipo village became one of the epicenters of the epidemic, and had, at one point, teams of over 200 national and international personnel. While much of their food and equipment was brought in by helicopter, the response teams nonetheless consumed some local goods, including domestic livestock, water (for washing) and products for sale at the market.

One of the most common complaints we heard against these response teams, was that they had increased the cost of living for ordinary people. As one man explained, with reference to the Twa who Nkundo people employ to work in their fields:

“We used to pay 1,000FC for a field, now we have to pay 2,000FC or more!”

This increase in the cost of labor was due to the fact that workers were being paid up to 8,000FC for a day’s work (such as digging latrines or building fences) and had therefore begun to refuse the exploitatively low pay that they had received in the past for hard agricultural labor.

Others found work for the response washing clothes, fetching water, acting as security guards or building structures. All of these activities had an impact on local labor economies, just as the sale of domestic livestock at ‘foreigner prices’ (*ntalo ya mindele* in Lingala), impacted the market price of livestock.

The relatively sudden imbalances in wealth between those who had worked for the response and those who had not, also created a lot of resentment and bad feeling (*motema mabe* in

Lingala) between neighbors and friends, and within families. In some cases, the employment of young men, and their rapid acquisition of wealth, led to intergenerational conflict.

Operational recommendations

» **Social scientists should be deployed to conduct research with communities to determine potential impacts and conduct a rapid assessment based on a study of local economies and the labor and resources the response team will require**

» **Social scientists should also assess the impacts of privileging one generation over another in terms of employment. It may be beneficial to ask all village elders to suggest several young people from their own family who would be interested in working, so that certain families do not benefit more than others.**

3.1.2 FOOD CRISIS

Several nurses, particularly in the smallest villages, who were very concerned about a looming food crisis. They spoke of an alarming rise in the number of malnourished children they were seeing. They attributed this to the following 6 factors:

(1) While working for the response, people had neglected work in their fields; (2) Survivors suffering from post-Ebola syndrome, and families decimated by the epidemic no longer had the labor-power necessary to work on their fields; (3) Contacts – as well as others in the community – had stayed away from their fields out of necessity (to stay isolated and not to travel), or fear, during the active outbreak; (4) Due to the effects of the response on the local economy, people were now unable to afford the (Twa) agricultural labor they had previously relied upon; (5) Fear and stigma

during and immediately after the epidemic meant that, on the one hand, people were prevented from selling their agricultural or forest products in other villages, and on the other hand, traders no longer came to sell goods in their villages; (6) Fear surrounding bushmeat meant that children were no longer receiving an important source of protein, and were increasingly presenting to health centers with kwashiorkor.

Several members of the community expressed frustration and resentment that only directly-affected families had received food aid, and yet the food crisis would affect almost everyone.

Operational recommendations

» During the outbreak, labor should be divided in a predictable, rather than haphazard fashion, so that people do not waste the morning hours (when much agricultural labor is undertaken) waiting at the coordination office to see if they will be offered work. All employees and laborers should work in shifts or on rotation, with adequate rest days built in so that they can work on their fields.

» Communications teams should prioritize the de-stigmatization of affected communities in the surrounding region, so that markets and other economic activities can resume as soon as the epidemic is declared over.

» Response teams and their local partners should consider providing victims, survivors and contacts who were unable to undertake subsistence activities during the active phase of the epidemic with pest-resistant seeds of manioc, rice, soy, legumes and vegetables to kick-start their subsistence activities.

3.1.3 LOST PROPERTY

The first complaint of every affected family which participated in the research, was that response teams (Croix Rouge RDC) had burned items belonging to the patient or the deceased and had not replaced those items nor offered compensation. This has also been reported for previous epidemics.³⁶

For the families involved, these were often valuable items, which were difficult to replace, or required monetary resources which they did not possess, such as beds and mattresses. One man explained to us that his mobile phone had been

destroyed when decontamination teams sprayed him and his possessions with chlorine.

Some people acknowledged that they had received small tokens of compensation, but the majority assured us that they had received no replacement or compensation for their loss. The experience was often a traumatic one which people felt augmented stigmatization.

The issue was even more complex in cases where families had, in fear and panic, destroyed or threw away other items, such as pots and pans, without instruction from response teams.

Operational recommendation

» It is important that communications teams address clearly which personal possessions run the risk of contaminating others (e.g. soiled mattresses), and which do not (e.g. metal pots and pans).

3.1.4 DEBT AND FUNERARY COSTS

When a man dies, his widow becomes responsible for the debts he had accrued while alive. These debts are often connected to the family's home (building a house out of durable materials such as bricks or a tin roof, adding doors, building beds or tables). Sometimes they are for purchases such as a radio or bicycle. In any case, they were always incurred by a family with the anticipation that the couple's combined labor would eventually result in the debt being paid off. When one person dies – and especially when this is the husband – the widow(er) finds themselves in a very difficult situation, often unable to pay off the debt.

Widow(er)s often have many children (sometimes up to 12). Not all of these are biological children, but they remain children for whom the couple was responsible. Caring for these children without the help of their spouse also becomes incredibly difficult, especially as older children's school fees become increasingly expensive. Several widows lamented that they no longer had the money to pay for children who were in their final year of school and who had been progressing well and had been hoping to pass their secondary school certificate that year.

These economic difficulties are compounded by the fact that funerals and funerary rituals are themselves very expensive. Families must pay for

³⁶ Epelboin et al (2008).

the coffin and burial, but they must also provide food, drink and housing for all of the extended family and friends who arrive to mourn the deceased. Often, the mourning period does not end until one final day of celebration and feasting is organized, meaning that bereaved families who cannot afford to organize a large feast, must continue feeding guests while they try to gather the resources necessary for the feast.

Other families explained that when they travelled to the ETC for treatment, or to be close to a sick relative, or during the extended mourning period, household items and domestic livestock had been destroyed, consumed or stolen by neighbors, in-laws and guests. On top of these costs, widow(er)s must typically pay a customary fine (called *nongo* in Lingala) to their in-laws when their spouse dies.

Operational recommendations

» **Provide school fees for children of victims (orphans) and of survivors, often unable to work because of post-Ebola syndrome, for one year.**

» **Provide widows, widowers and/or the parents of victims with a donation to contribute to funerary expenses and customary debts.**

3.1.5 EMBEZZLEMENT & UNFULFILLED PROMISES

Dozens of stories circulate in Equateur about the embezzlement of Ebola funds. Communities which were not directly affected by the outbreak say that the epidemic was fabricated in order to attract the funding of big international donors. Those who were directly affected lament the fact that they 'have not benefitted' while national and regional elites and international respondents have made thousands of dollars through their participation in the response.

Stories also circulated among both affected communities and international response teams that local administrative leaders have embezzled not only Ebola funds, but the material and equipment, such as motorbikes and electric generators, which (it is said) were intended for affected communities or rural hospitals and health centers.

Several of the RECO who participated in the research expressed anger that their names had not appeared on the lists of RECO who received a

'bonus' directly from the Minister of Health. Many pointed to corruption and nepotism on the part of their superiors.

While the finger of blame is sometimes pointed at specific individuals in positions of power, other people are not as sure about who is to blame for the fact that the most affected communities feel dispossessed. For many people, the differences between different international actors and NGOs are not clear. Oftentimes, they were grouped together, and (as perceived representatives of UNICEF) so were we, with many people asking us:

“So, you are just going to leave us like this?”

When people spoke of seeing 'no visible impact', they were referring to the vast displays of wealth they had witnessed with the logistics (cars, motorbikes, helicopters, airplanes, electric generators) of the response, and the fact that, despite still being in need (many thousands more people will die from malaria than Ebola in Equateur this year), they would no longer benefit from this when the response teams left. This led to protests when NGOs began to pull out their personnel and equipment to assist in Beni.

Part of the reason for this disappointment was a conviction that various actors – politicians, national and international responders, and local administrators – had promised to leave this equipment for affected communities, or build hospitals, health centers and maternity clinics.

Response teams should never make promises about the support which will follow an Ebola outbreak, unless they will be part of a program funded to undertake this – differences between humanitarian assistant and development work should be emphasized.

Operational recommendations

» **Response teams should work with national and regional authorities to minimize embezzlement and corruption as it relates to Ebola resources.**

Capacity-building recommendation

» **Long-term investment in affected communities should be an integral part of response efforts, at least for a one-year recovery period.**

3.2 HEALTH IMPACTS

This section outlines the impacts that EVD has on survivors' health, including their mental health and the psycho-social impacts of monitoring Ebola survivors for a lingering infection which could lead them to be contagious to others. It also considers the mental and physical health of EVD survivors who were never registered and feelings of exclusion and resentment towards the response.

3.2.1 POST-EBOLA SYNDROME

Until the West Africa crisis, post-Ebola syndrome was a rumored but little-studied after-effect of EVD. Symptoms include joint and muscle pain, eye problems, including blindness, various neurological problems, and other ailments.

Most of the survivors who participated in the research alluded to continuous ill health, physical pain and in some cases, neurological conditions such as confusion and forgetfulness, and mental health problems connected to trauma. Several people spoke of conditions (pain and weakness) so severe that they were still unable to work.

ALIMA is currently following all survivors in order to monitor this syndrome, and is also treating certain conditions, such as the eye problems. While an earlier report suggested that, towards the end of the epidemic (early July 2018), this monitoring was burdensome on survivors because it was extensive and almost daily,³⁷ during our interviews (September 2018), survivors had undergone some time without surveillance, and were eager for the check-ups and treatment to begin again. They were particularly concerned with finding treatment for their joint pain. Where these visits had caused them to feel some shame before, they were now welcomed as a continuation of care.

It is important to follow EVD survivors in order to determine the varied symptoms following EVD infection and to determine the best care. However, a delicate balance must be struck between continuing the care of EVD survivors and burdening their time with too many tests and check-ups.

3.2.2 MENTAL HEALTH

Mental health is a very important issue in rural Congo, even as it is almost completely neglected by national biomedical structures. Following an Ebola epidemic, mental health issues arise from

the trauma of the disease, from the trauma of losing family members, and from the social stigmatization experienced by many EVD survivors.

Mental health requires a 'whole of society' approach, and psychological support should be accompanied by communication which reduce stigma in the broader community.³⁸ Families of victims, especially widows and orphaned children, are also in need of continued psycho-social support. If resources permit, women should have the possibility of talking to female psychologists.

Capacity-building recommendation

» **After the epidemic, survivors should be supported by the creation of community support groups, which can be established in collaboration with ANVE.**

3.2.3 SEXUAL TRANSMISSION OF EBOLA

Viral traces of Ebola have been found to persist in semen, vaginal secretions and breastmilk after a patient recovers and no longer has any detectable virus in other bodily fluids.³⁹ In West Africa, there have been cases of the sexual transmission of Ebola, and of the transmission from mother to breastfeeding infant.

One important part of ALIMA's post-Ebola check-ups, is to monitor the virus in the body fluids of survivors. However, the possibility of remaining contagious is one of the sources of stigmatization against which survivors must struggle, and so the ALIMA teams must make sure that these investigations do not jeopardize the social standing of their patients.

There are also challenges in getting survivors to use condoms during sexual intercourse, as condoms are often associated with disease or with a socially unacceptable level of sexual promiscuity.

³⁷ Duda (2018).

³⁸ IASC (2008; 2015).

³⁹ Sissoko et al (2017).

EVD survivors have emphasized the need for those conducting tests on body fluids to be non-local staff, to assure that their confidentiality is protected. In order to minimize the stigma which could be attached to such tests, they should be conducted as part of a comprehensive check-up. Efforts should be made to minimize alarm in the community, while providing survivors with the information necessary to protect themselves and others.

Operational recommendation

» In order to destigmatize the use of condoms and encourage EVD survivors to use them, village-wide regional campaigns should be undertaken to encourage their use.

3.2.4 UNREGISTERED PATIENTS

Following the epidemic, some health actors have felt overwhelmed and frustrated by the number of unregistered patients who have subsequently claimed to have had Ebola.

Many of the health actors who participated in the research attributed this to the support EVD survivors and families of victims have received during and following the epidemic. They claim that those who may have had Ebola, but who fled

the response out of fear (and perhaps even some people who were sick but did not have Ebola) are now making claims so that they too may benefit from this support.

This is a challenging ethical question with no easy answer: What to do with those people who were sick, but were too afraid to collaborate with the Ebola response teams during the outbreak? Do they deserve the same level of care as other patients who passed through the ETCs? Or should they receive no care in order to encourage people to collaborate with the system if they wish to benefit from it?

This question becomes all the more pressing when one considers the EVD survivors and families of victims who were affected at the onset of the epidemic when the response had not yet arrived. As a family member of the first confirmed case of Ebola, in Ikoko Impenge village, told us, referring to international response team personnel:

*“We were the first to fall sick,
and yet we have not benefitted
from your presence.”*

3.3 SOCIAL IMPACTS

This section outlines the enduring social repercussions of the Ebola epidemic, and draws attention to organizations, such as the National Association of Ebola Vanquishers (ANVE), which can be collaborated with and supported in order to aid both survivors and their broader communities.

3.3.1 STIGMA

Stigma is multifaceted and has had an impact on many different people; from local healers or Batwa who were thought to be at the origin of the Ebola ‘curse’, to survivors, families of victims, and local health actors, who, in some cases, continue to be referred to as ‘contaminated.’

For the latter, this is often expressed through avoidance and rejection, with several health workers and survivors telling us that they have been unable to visit family members, who refuse to offer them food and housing. It is also experienced in the form of mockery and jeering.

People often fear direct contact, although they may also refuse to eat food cooked by a survivor, or to touch goods or money handled by a survivor. This fear may be particularly acute because of the ongoing follow-up exams, which seek to monitor the presence of the virus in survivors’ body fluids.

Many RECO and doctors have experienced a rejection by some members of society, initially because they were rumored to be collaborating with a project to infect people with Ebola for financial gain, and subsequently because of the large amounts of money they are said to have made by participating in the coordination.

On the other hand, some rural health actors have found themselves mocked for having lost so much money during the epidemic, and for being unable to afford their children’s school fees. *See also, 2.3.4: Free health care.*

Discrimination of survivors and the families of victims is ongoing and should continuously be addressed by the response, including in the months following the end of the epidemic.⁴⁰

Celebrations organized when survivors leave ETCs, in which broader communities can participate, and are reassured that it is safe to interact with survivors, are an excellent way of reintegrating survivors.

Capacity-building recommendations

» Stigmatization of survivors can be minimized by donating sewing machines, bicycle repair kits to ANVE, so that survivors can play a more important role in the community.

» ANVE should be supported in the establishment of support groups for those directly affected by the epidemic, so that it can reach out to more isolated families and survivors, who do not live in proximity to its base in Itipo.

» ANVE should also be supported in reaching out to other survivor groups in West Africa, in creating a national network in DRC and in applying for funds for its own projects.

3.3.2 TORN SOCIAL FABRIC

Fear of contagion led many people to stop shaking hands, to distance themselves physically from others, to stop visiting others and to limit their attendance at funerals. This fear and lack of trust continues to erode relationships and to make people feel afraid and isolated.

Many people describe the epidemic as akin to ‘war’. They are referring to the chaos, the fear, the ways in which they had to mobilize all their resources in the fight to stop the disease, and in the losses they suffered.

Several people told us that their pain would be ease if a hospital, a maternity ward, a school, or another symbolic building could be constructed or refurbished in order to mark this momentous event and honor those whose lives were lost.

Capacity-building recommendation

» A ‘whole society’ approach should be used to develop plans with affected communities for appropriate memorialization of the epidemic, its victims and the sacrifices and losses of affected communities.

⁴⁰ ERAP (2014); Arwady et al (2014).

CONCLUSION

Evaluating epidemic responses is crucial to improving response strategy for future epidemics. For example, it is widely held that the 2014-16 Ebola outbreak in West Africa spiraled out of control because national and international responses did not draw on lessons learned from previous epidemics, such as the work of anthropologists Epelboin and the Hewletts.⁴¹ These evaluations had emphasized the importance of community engagement and the problems associated with opaque isolation units and treatments, and the rumors surrounding foreign medical personnel and their protective equipment – but these mistakes were repeated in West Africa.

DR Congo's Ministry of Public Health and National Biomedical Institut (INRB) house many experts who are veterans of Ebola epidemics, such as Jean-Jacques Muyembe, the Congolese epidemiologist, who has investigated all ten of DR Congo's epidemics since 1976. Building on the insights of previous anthropologists, the advice offered by Professor Muyembe during a meeting with the author in 2017, and ongoing research with communities affected by DR Congo's 7th Ebola epidemic (2014) in another equatorial region,⁴² this report is based on recommendations made by various local actors (health officials and community health workers, government officials and administrators, community leaders, Ebola survivors and their families, and the families of victims) affected by DR Congo's 9th Ebola epidemic. Building on these recommendations, this report proposes a Grassroots Model for Epidemic Response.

The Grassroots Model for Epidemic Response has four key principles. The first is a 'whole society' approach that attends not only to those individuals directly affected by the outbreak, but also to their broader communities. Doing so can minimize fear, stigmatization and resentment, and help to rebuild social fabrics fragilized during the epidemic.

The second is a commitment to inclusivity which appreciates that 'communities' are not homogenous and prioritizes the engagement of marginalized and vulnerable populations. This includes an attention to gender, to inter-generational dynamics, to ethnic, religious or caste minorities, and to vulnerable populations such as widow(er)s, pregnant women, the infirm and the elderly.

The third is that attention to local stakes can help responders appreciate why Ebola epidemics are understood through the lens of broader issues such as politics, economics and religion. Previously classed as 'rumors', these alternative explanations are often very revealing about perceptions of the state and health system, and about social tensions. Attending to these dynamics is of the utmost importance for a successful epidemic response.

Finally, a commitment to utilizing pre-existing epidemic response capacity ensures that interventions build on the social and cultural resources of the communities they seek to support. This report has presented the local capacities of the health system in detail (*see: 2.1.3 Community health workers*) and has demonstrated that their integration from the very start of the epidemic is integral to an effective and coordinated response.

The overall finding of the report is that an Ebola epidemic, along with the way the response itself is conducted, can have significant social, psychological, economic, and health impacts for the communities involved. By providing a close, qualitative reportage on perceptions of the epidemic and the response in Equateur Province, the report aims to render tangible the social, political and economic

⁴¹ Hewlett & Amola 2003; Hewlett & Hewlett 2008; Hewlett 2016; Epelboin & Formenty 2011; Epelboin, Odugleh-Kolev et al. 2014.

⁴² Alcaya-Stevens & Giles-Vernick (forthcoming); Alcaya-Stevens (forthcoming).

dimensions of an Ebola epidemic and to offer recommendations for the response which prepare communities for life 'post-Ebola' at each stage of an intervention.

Epidemic management focuses on what needs to be done before, during and after an epidemic. Each section of the report examines one of these temporal stages. During 'preparedness', the focus is on reducing vulnerability to disaster and strengthening capacity, surveillance and early detection. 'Response' begins with a coordinated and rapid investigation, and then the implementation of appropriate control and case management, which is supported at each step and in every aspect by robust, clear and two-way communication. Finally, 'recovery' focuses on evaluation and accompanies affected communities in their lives 'post-Ebola.' Each stage should seek to minimise the health, social and economic impacts of the epidemic.

But as this report demonstrates, the DRC's 9th Ebola epidemic was a watershed moment in Ebola epidemic response. Response teams have learned from the past, and increasingly prioritize national leadership and local community engagement, partnership with trusted leaders, dignified burials, and improvements in patient care. The deployment of an experimental vaccine provided a new tool for response teams to break the chain of transmission. The Biosecure Emergency Care Units (CUBE) deployed by the NGO, ALIMA provided new treatment options for case management, and were described as 'paradise-like' by several participants in this research. Building on these improvements, this report has provided a wide range of recommendations, drawn from discussions with local actors, which can further strengthen future Ebola epidemic responses.

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