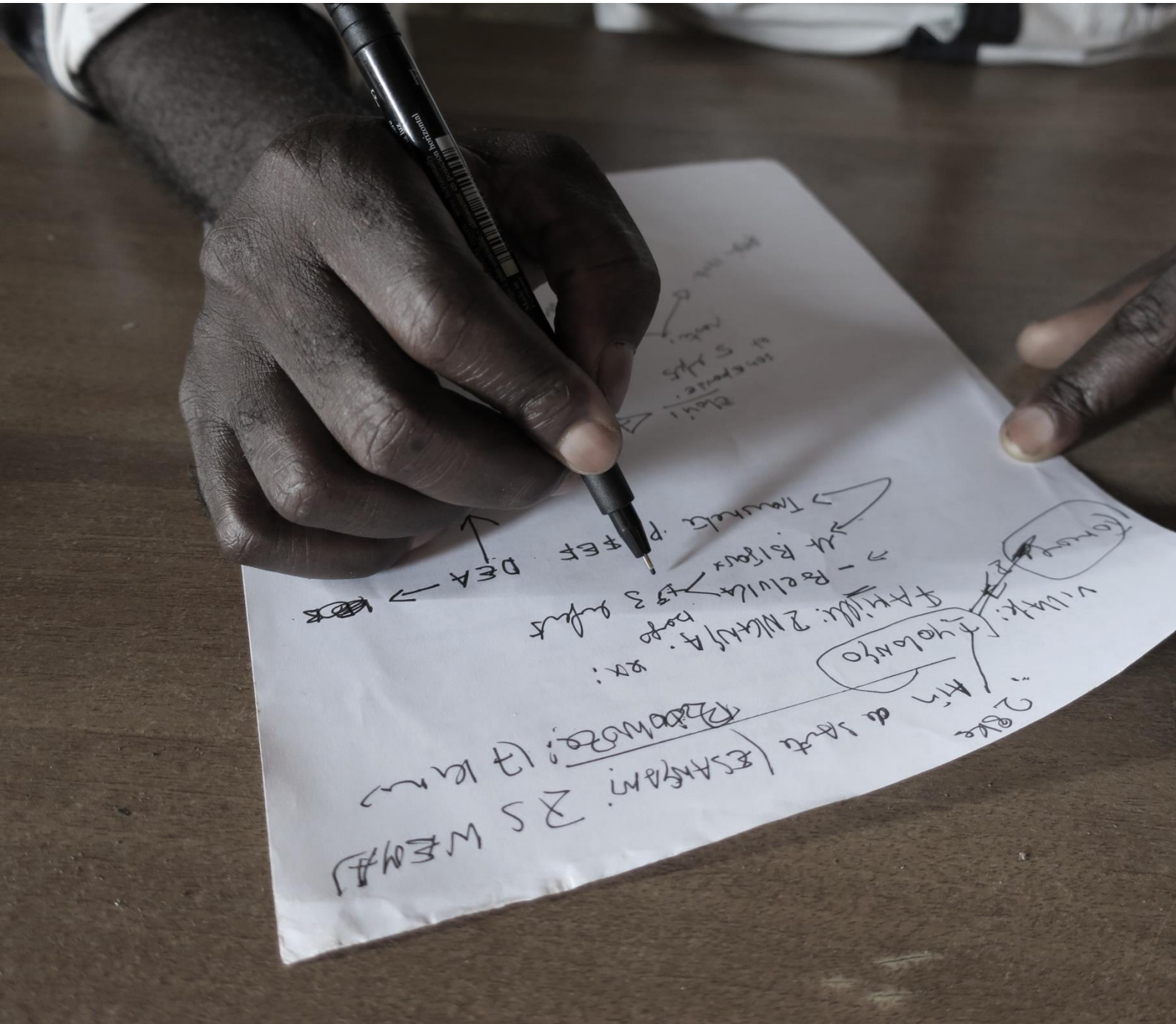
# PLANNING FOR **POST-EBOLA**

LESSONS LEARNED FROM DR CONGO'S 9TH EPIDEMIC

# PART II | RESPONSE



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Lys Alcayna-Stevens, 2018

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# ACRONYMS AND ABBREVIATIONS

| | |
|---|---|
| **AC** | Community Animators (*Animateur Communautaire*)[1] |
| **ALIMA** | Alliance for International Medical Action |
| **ANVE** | National Association of Ebola Vanquishers (*Association National des Vainqueurs d'Ebola*) |
| **APS** | Psycho-social assistant (*Assistant Psycho-social*) |
| **AT** | Territorial Administrator (*Administrateur du Territoire*) |
| **CAC** | Community outreach units (*Cellule d'Animation Communautaire*) |
| **CBO** | Community-based organization |
| **CE** | Community engagement |
| **CODESA** | Local health committees (*Comité de Développement de l'aire de Santé*) |
| **DPS** | Provisional health division (*Division Provincial de Santé*) |
| **EP** | Protective equipment (*équipement protective*) |
| **ETC** | Ebola Treatment Center |
| **EVD** | Ebola Virus Disease |
| **FPIC** | Free prior and informed consent |
| **INRB** | National Institute of Biomedical Research (*Institut National de Recherche Biomédicale*) |
| **MPH** | Ministry of Public Health |
| **MCZ** | Medical Inspector of the Health Zone (*Médecin Chef de Zone*) |
| **MSF** | Doctors Without Borders (*Médecins Sans Frontières*) |
| **PA** | Indigenous people (*Peuple Autochtone*) |
| **PBF** | Performance-based financing |
| **PPE** | Personal protective equipment |
| **RCCE** | Risk communication and community engagement |
| **RECO** | Community health workers (*relais communautaire*) |
| **SANRU** | Rural Health Program (*Projet Santé Rurale*) |
| **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.

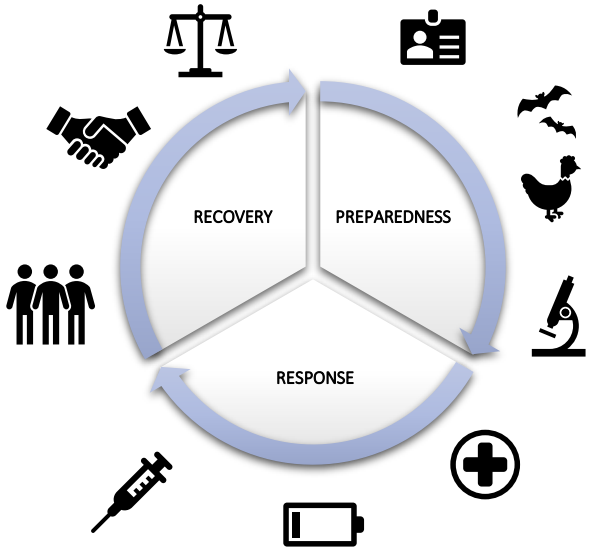
Epidemic management focuses on what needs to be done before, during and after an epidemic in order to minimize the health, social and economic impacts of the epidemic. This report, **Part Two: Response**, which provides information and recommendations on transmission, risk communication, contact tracing, vaccine deployment, case management, and burials. It is part of a series which examines each one of the temporal stages of an epidemic from the report 'Planning for Post-Ebola' (Alcayna-Stevens 2018). The other reports in the series are: **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; and **Part Three: Recovery**, which 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 series 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 of the reports in this series 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.

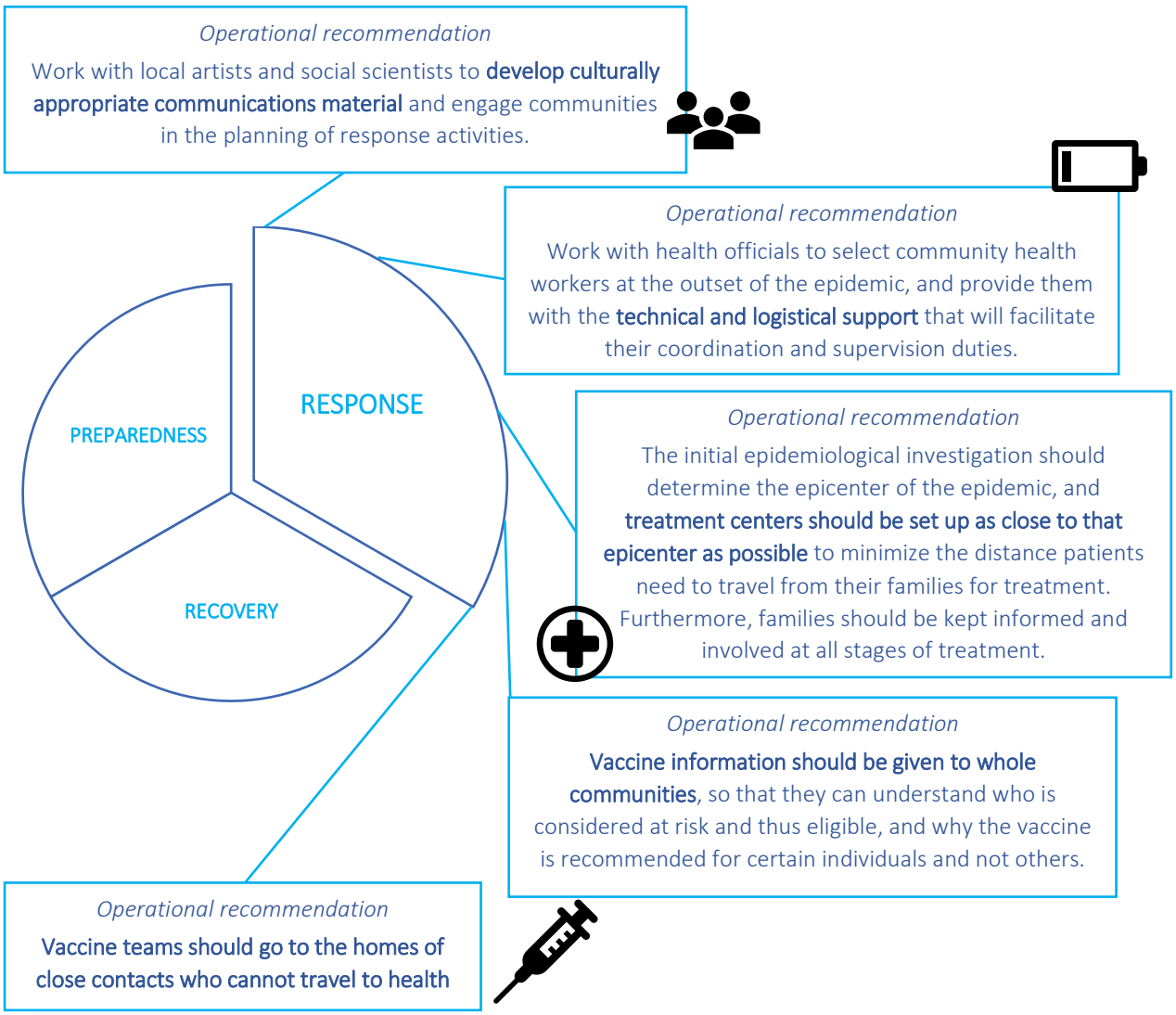
(4) UTILIZING PRE-EXISTING EPIDEMIC RESPONSE CAPACITY ensures that interventions build on
the social and cultural resources of the communities they seek to support.

Lys Alcayna-Stevens, 2018
Planning for Post-Ebola: Lessons learned from DR Congo's 9th epidemic
New York: Communication for Development, UNICEF

# 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.

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# 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. [2] 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 be 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.[3] 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.[4] 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

[2] Ripoll et al (2018).
[3] Abramowitz et al (2017).
[4] Bedford (2018a).

was discovered that the response was paying the owners of taxi motorcycles and not the taximen themselves for their risk communication activities.[5] 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.

[5] 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 ties 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 heath actors.

It is important to remain aware that recruitment of traditional leaders runs the risk of ignoring the needs and voices of marginalized populations.[6] *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

[6] 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.[7]

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. [8]

*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.**

[7] More detail is provided in Duda (2018).

[8] 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 to 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 PA 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.[9] 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 is 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

[9] 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.[10]

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

[10] 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 unmutilated 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.**

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