

Special feature

Responding to Ebola in the Democratic Republic of Congo

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**Humanitarian
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About HPN

The Humanitarian Practice Network at ODI is an independent forum where field workers, managers and policy-makers in the humanitarian sector share information, analysis and experience. The views and opinions expressed in HPN's publications do not necessarily state or reflect those of the Humanitarian Policy Group or ODI.



Cover photo: 16 January 2019 - Beni, Democratic Republic of Congo. Health workers put their gloves on before checking patients at the hospital.
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Editorial



This edition of *Humanitarian Exchange*, co-edited with Anne Harmer, focuses on the response to the Ebola outbreak in the Democratic Republic of Congo (DRC).¹ Although at the time of publication the outbreak appeared to have ended, over its course it claimed 2,200 lives, with more than 3,300 infected, making this the world's second-largest outbreak ever. In the lead article, Natalie Roberts reflects on the extent to which humanitarian actors have applied learning from the outbreak in West Africa in 2014–2016. Richard Kojan and colleagues report on the NGO ALIMA's flexible, patient-centred approach to reducing mortality, Marcela Ascuntar reflects on lessons learned from community feedback and Bernard Balibuno, Emanuel Mbuna Badjonga and Howard Mollett highlight the crucial role faith-based organisations have played in the response.

In their article, Theresa Jones, Noé Kasali and Olivia Tulloch outline the work of the Bethesda counselling centre in Beni, which provides support to grieving families. Reflecting on findings from a recent assessment by Translators without Borders, Ellie Kemp describes the challenges involved in providing clear and accessible information on Ebola and the response, and Sung Joon Park and colleagues explain how humane care and treatment can help increase trust and confidence in the response. Stephen Mugamba and his co-authors highlight the importance of community involvement in Ebola research, and Gillian McKay and her co-authors examine the impact of the Ebola outbreak and response on sexual and reproductive health services. Stacey Mearns, Kiryn Lanning and Michelle Gayer present an Ebola Readiness Roadmap to support NGOs in preparing for an outbreak, while Edward Kumakech, Maurice Sadlier, Aidan Sinnott and Dan Irvine report on a Gap Analysis tool looking at the communication, community engagement and compliance tracking activities that need to be in place before an Ebola vaccine is deployed. Emanuele Bruni and colleagues describe the development of a new monitoring and evaluation framework for strategic response planning. The edition ends with an article by Adelia Fairbanks, who argues for an acceptance strategy in the DRC to improve security and access for responding agencies.

Editorial photos:

Top left: People are seen lining up to get their temperature checked at an MSF supported triage, before heading into Bunia's general hospital.

© John Wessels MSF

Top: October 2018, North Kivu, DR Congo. Martine Kavuchio, 30, shows her daughter Christine Botulu, 6, the handwashing techniques she learned at the health centre as part of Mercy Corps' Ebola response.

© Rudy Nkombo for Mercy Corps

Bottom middle: Women listen to a talk about Ebola in a mosque in Goma DRC.

© Tommy Trenchard/CAFOD

Bottom middle: Two surveillance officers discussing Key Performance Indicators in the Emergency Operations Center in Beni, North Kivu.

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As always, we welcome any comments or feedback, which can be sent to

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¹ Anne is Manager of Elrha's Research for Health in Humanitarian Crises (R2HC) Programme, funded by DFID, Wellcome and the UK National Institute for Health Research. Find out more at www.elrha.org/r2hc.



People are seen lining up to get their temperature checked at an MSF supported triage, before heading into Bunia's general hospital.

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Responding to Ebola in the Democratic Republic of Congo

Ebola and innovation: examining the approach to the Nord Kivu epidemic

Natalie Roberts

Within four months of the first notification of Ebola cases in August 2018, the Nord Kivu (and Ituri) Ebola epidemic had become the second-largest on record. Notwithstanding a rapid and massive mobilisation of resources, the outbreak continued beyond the most pessimistic predictions and the case fatality rate (the proportion of people with the infection who die from it) remained static at 66%. Despite numerous lesson-learning exercises following the Ebola epidemic in West Africa in 2014–2016, and despite the development of new vaccines and treatments, after 3,444 cases and 2,264 deaths it is difficult to claim that outcomes are better this time around.

At the same time, the response to the Nord Kivu epidemic was marked by extensive innovation and the rapid translation of ideas and inventions into practice. While previous outbreaks of Ebola had been small and arguably self-limiting, the duration and scale of the epidemic in West Africa led to the development of ideas, techniques and products which were finally put to the test in the DRC. Some are already proving successful, notably the use of a vaccine which seems to have not only protected many health workers from infection, but also had an impact on the scale and duration of the epidemic.

There are three key questions in the design of any epidemic response: how to protect the responders; how to reduce the number of infected people, i.e. the incidence of the disease; and how to reduce the number of dead, i.e. the lethality of the disease. These questions are framed within the timescale and geographical spread of an epidemic, the social and political dimensions of the response and the activities of the institutions in charge of it. The aim should be to minimise the negative political and socio-economic consequences of the epidemic, or at least not exacerbate them.

In the aftermath of the West African epidemic, MSF CRASH and Epicentre, an MSF satellite institution in charge of epidemiology, began a research study to investigate different practices proposed or tested by responders to address these questions. Following the Nord Kivu outbreak this work will be reviewed and updated, to inform future approaches to Ebola and epidemics in general. Some initial considerations are detailed here.

Protecting responders

In an outbreak of infectious disease the initial priority is to protect the responders, who are essential to the success of the intervention. This is imperative in an Ebola epidemic, as health workers are at disproportionate risk of infection. Many fall sick or die from the disease, while fear of infection leads others to stop working and health facilities to close. This reduces the capacity of the response and weakens general healthcare provision. In addition, health workers who fall sick with Ebola increase the disease burden and therefore the workload for those still working. Infected health workers also act as spreaders of the disease, and in previous epidemics have been identified as one of the principal mechanisms of transmission.

Organisations responding to Ebola outbreaks have adopted a model of Personal Protective Equipment (PPE) intended to decrease the risks to health workers and other frontline responders likely to come into contact with infected bodily fluids. However, the typical configuration of 'Full PPE' is hot, heavy, expensive, restrictive and not adapted to the situations in which it is used. Medical personnel working in treatment centres complain that patient care becomes impractical or impossible. It is unrealistic for personnel in peripheral health facilities to continuously wear 'Full PPE' just in case a patient with non-specific symptoms turns out to be suffering from Ebola. Burial teams complain that the yellow suits and facemasks provoke fear and aggression, resulting in physical attacks. Attempting to address these problems, MSF France trialled algorithms in Nord Kivu health facilities to recommend the appropriate configuration of PPE according to the probable risk each patient poses to the health worker. ALIMA, a French, African-based NGO, developed the CUBE, a transparent bio-secure unit designed to facilitate the monitoring and care of Ebola patients while reducing time health workers spend in PPE.

Meanwhile, a vaccine shown to confer protection against infection from ten days after administration was supposed to be available to all 'frontline' Ebola workers in DRC. Despite initial concerns, acceptance was high and there was consistent demand for vaccination. However, a number of challenges and shortcomings limited the full impact of the intervention. First, traditional healers and staff in private clinics provide a considerable proportion of health services in DRC and are at high

risk of infection, but were not included in the eligibility criteria. Second, although few eligible workers refused, not all eventually received a vaccine. Waiting lists were long and the vaccination process, under the management of WHO and the Congolese Ministry of Health (MOH), was complex and slow, partly as a result of uncertainty about the use and study of an unregistered product. Some MSF and MOH staff working in MSF facilities believed that they were not allowed time away from work; side-effects of vaccination can be debilitating and last several days. Some reported that high demand for limited stocks had made the vaccine a commodity, and suspected that their dose had been sold to someone else. Despite these shortcomings, however, the use of the vaccine during the Nord Kivu epidemic is likely to be the primary reason for the significant reduction in health worker infections compared to West Africa.

In addition to preventive vaccination, WHO recommends antibody therapies be considered as prophylaxis for ‘frontline’ health workers with a high risk of exposure to Ebola. However, Congolese health workers, particularly if not working within dedicated Ebola facilities, were not generally aware of this possibility. Incidents of exposure were under-reported, and post-exposure prophylaxis was under-used.

Reducing the number of infected people

As Ebola sufferers are thought to become contagious only when symptomatic, efforts have long been made to convince people to submit to isolation as soon as they fall ill, to try to curtail disease spread. These practices often fail. Who would agree to be admitted to an Ebola centre knowing that the majority of patients do not leave alive? Who would go to an Ebola centre just to be tested, when they are more likely to be suffering from malaria or gastroenteritis?

One common approach to try to stop transmission is contact tracing, where people who have come into contact with a person confirmed as infected are identified and followed up daily for 21 days, with the aim of isolating them rapidly if they become ill. Congolese contact tracing teams struggled due to the scale and geographic spread of the epidemic, the mobility of the local population and the reluctance of symptomatic contacts to be placed in isolation. The World Food Programme began providing food to contacts so they wouldn’t have to leave their homes to go to the market and could be more easily monitored. This probably increased compliance with monitoring, but it also increased the number of people identifying themselves as a contact, many unnecessarily. As well as further overwhelming the system, this could help explain why men were disproportionately listed as contacts, although women and children were actually more likely to be infected.

Understanding the mechanisms of Ebola transmission is essential to designing a response that aims to reduce the number of infected individuals. In DRC, people were most frequently infected through contact with a sick member of their family or social group, often while providing care. Nosocomial transmission

was also important, as vaccinating health workers did not prevent transmission from patient to patient linked to poor hygiene practices within health facilities, such as the sharing of beds or the reuse of medical equipment. The third major risk factor for infection in DRC was participation in funeral rites.

Disease control practices that rely on behaviour change are slow and can be resisted. For example, it is unrealistic to expect family members to stop caring for sick loved ones, the main risk factor behind community transmission. The sick in Nord Kivu are usually cared for at home, with visits to local traditional healers, pharmacies or clinics. Government health facilities are considered mainly for illnesses that are not resolving, with relatives staying to provide general nursing care. The practice of separating sick patients from their family to isolate them in an Ebola centre is considered unacceptable, and centres are unwelcoming and provide little support for families. Caregivers have few options but to go home and wait to see if they themselves fall sick.

Rather than attempting to change long-standing behaviour, MSF France and Epicentre wanted to use antibody therapies as post-exposure prophylaxis (PEP) for family caregivers of confirmed Ebola cases. This would offer individuals at elevated risk of having been infected a potentially effective intervention to stop them developing the disease, and to encourage them to comply with monitoring. If PEP is completely effective the caregiver would not become sick, so should not become contagious. Even if not, the disease would potentially be milder and they could be isolated and given appropriate care as soon as symptoms appeared. However, this practice was not sanctioned by the WHO and Congolese health authorities, apparently because of concerns about supply or that antibody treatments might reduce the long-term protective effect of the vaccine.

Various practices attempted to reduce nosocomial transmission. Decontamination of health facilities reporting an Ebola case became a routine component of the response, but is labour-intensive and does not prevent recontamination of that facility if another infected patient arrives. Decontamination teams wearing suits and masks also signal the presence of Ebola, deterring patients from using centres. Various actors distributed additional hygiene supplies and provided staff training, but the large number of health facilities and the fact that most were understaffed and lacked basic infrastructure such as water supply made this activity relatively useless.

Ultimately, vaccination could prove an effective method to stop spread, or at least to prevent large outbreaks. Two vaccines were made available for study during the DRC epidemic, including one whose efficacy had been proven in West Africa. The challenge remains to design strategies that identify the right people to receive the right vaccine at the right time, taking into consideration supply limitations and constraints such as ultra-low temperature cold chain management. Difficulties in contact tracing meant that the WHO-led ring vaccination strategy, which depends on an accurate and comprehensive identification of contacts, did not adequately control the spread of disease.

Reducing the number of deaths

A clinical trial of experimental treatments during the Nord Kivu epidemic identified two effective monoclonal antibody treatments effective in the treatment of Ebola.¹ For an increased chance of survival, Ebola sufferers should receive one of these curative drugs together with supportive care, such as fluid rehydration, adapted to the severity of illness. Neither of these measures is effective when the illness is too advanced, so early detection and treatment is crucial.

Medical responders, notably ALIMA, WHO and the MOH, have pushed the boundaries of patient care. Innovations such as the CUBE and staff vaccination, the deployment of intensive care physicians and the use of critical care models have allowed high-level supportive care to be adapted to individual patient circumstances in a high-risk environment.

The availability of new treatments and laboratory diagnostics in DRC was suggested to encourage sick people to present earlier for testing and treatment. However, Congolese health promoters and local media spreading the message about treatments did not obviously reduce the average time between the development of symptoms and admission to an Ebola centre. Apart from centres being inhospitable and frightening, admission required passing via a gatekeeper, often a local healthcare provider. In response, MSF created small isolation areas within existing local health facilities where symptomatic patients could receive care while being tested for Ebola, reassured that they would be referred to a dedicated Ebola centre only if test results were positive. In Beni this appears to have reduced the average delay in treating patients who present to these health facilities. However, demonstrating an impact on overall case fatality rates would require the model to be deployed and studied more widely.

Some in MSF recommended financial assistance for Ebola patients or their families, to reduce the social and economic impact of infection with a stigmatising disease that results in prolonged disability or death. Apart from ensuring that affected individuals benefit directly from the massive resources dedicated to the Nord Kivu and Ituri Ebola response, this was surmised to be the quickest way to encourage people to positively engage with actors involved in the response. However, others within the organisation considered this too sensitive or complex, and the idea was not developed further. Direct financial support to Ebola victims was ultimately not adopted by any actor involved in the response.

Controversies: science versus innovation; science versus ethics

It is difficult to assess new practices ‘scientifically’, as they are by necessity guided by operational reasoning and experience,

rather than pre-existing evidence. Ebola outbreaks have become notable for the number and range of responders, all acting under time pressure to try to contain the epidemic. This leads to a maelstrom of promising ideas being implemented all at once: the opposite of traditional scientific research, where only one variable at a time is adjusted and the impact evaluated. The interactions between multiple interventions can result in outcomes greater than the sum of their parts, but are difficult to decipher: if a combination of early diagnosis and treatment and care provides the highest likelihood of survival for Ebola victims, where best to expend energy to reduce the overall case fatality rate? Traditional research is slow but thorough; innovative empirical practice has the benefit of speed. In any practice there is an obligation to document, analyse and evaluate in an attempt to improve outcomes. However, formal research protocols, designed to generate statistically significant evidence rather than inform current practice, must be carefully considered to avoid unnecessarily slowing the implementation of innovative ideas.

Attempting to modify practice in a timely but ethical manner within a context of uncertainty is challenging for humanitarian practitioners. As in West Africa, confusion and tensions arose around the use of ‘experimental’ or unregistered products during the Nord Kivu epidemic. For example, despite participating in frontline worker vaccination activities, MSF did not initially recommend vaccination to its own staff or stop unvaccinated personnel from entering high-risk situations. Internal debate focused on the ethics of endorsing an unregistered product and on giving personnel the right to choose without influencing their decision. The information provided to staff was ambiguous, often reflecting the perspective of an individual manager or MSF section. Some MSF managers concluded that there must be hidden concerns about vaccine safety given it was still part of a clinical study (which was in fact to confirm effectiveness). Others worried that vaccinated staff might develop a false sense of security and take excessive risks, so wanted to recommend only (unproven) PPE measures. One MSF section claimed it irresponsible to allow staff to expose themselves to risk by being in contact with Ebola patients without having been vaccinated; others felt that banning unvaccinated staff from treatment centres would put undue pressure on them to accept the vaccine. This issue was only resolved months after the start of the outbreak, when it became obvious that vaccinated staff were rarely becoming infected.

What next for Ebola and other epidemic responses?

With the Nord Kivu epidemic slowing, there is an opportunity for all actors to reflect on successes and failures in the response. For MSF, dissecting and understanding what approaches were attempted or rejected by different responders at different stages of the epidemic could help in creating working hypotheses for the future. Analysis of the response will lead to considerations specific to Ebola, but also reinforce recommendations for

1 Sabue Mulangu et al. (2019) ‘A randomized, controlled trial of Ebola virus disease therapeutics’ *New England Journal of Medicine* 381(24) (www.nejm.org/doi/pdf/10.1056/NEJMoa1910993).

planning any epidemic response, for example regular meetings to clarify response intentions with international and national actors and the health authorities in countries where outbreaks are most likely to occur. Given the likelihood of similar ‘Public Health Emergencies of International Concern’, it is important for MSF to study the organisation of the Ebola response, its management and funding, the actors involved and MSF’s own complicated relationship to it. Finally, examining the process of how humanitarian actors learn via trial and error during

scientific, ethical and political uncertainty can contribute to the development of a more robust operational response to dangerous epidemics.

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Reducing mortality from Ebola through a comprehensive, decentralised and integrated standard of care

Richard Kojan, Papys Lame, Eric Barte de Sainte Fare, Valérie Chanfreau, Mélanie Tarrabeau and Nicolas Mouly

Since 2014, ALIMA has been involved in the management of several Ebola outbreaks. Despite the implementation in North Kivu and Ituri of recommendations derived from analysis of previous episodes, there has been no significant improvement in case fatality rates. In Guinea between 2014 and 2016, for example, the case fatality rate was 66.7%,¹ while in the tenth and current outbreak in the Democratic Republic of Congo (DRC) the fatality rate was 65.9%.

ALIMA promotes a more flexible, comprehensive, integrated and patient-centred approach to reducing mortality. This approach seeks to strengthen the quality of care around three main axes:

- The clinical standard of care within Ebola Treatment Centres (ETCs) for confirmed cases.
- Outreach activities and decentralised and integrated standards of care for all patients, including suspected cases.
- The standard of care for Ebola survivors and their integration within the health system to ensure proper monitoring and follow-up.

Clinical standard of care within Ebola Treatment Centres

ALIMA developed an optimised standard of care for Ebola patients after the outbreak in West Africa. When the disease was discovered, clinical management standards were 40 years old. Since then, ALIMA has developed new care standards to reduce the disparity between the care delivered in Western countries and in our areas of intervention. The development of the Biosecure Emergency Chamber for Epidemics (CUBE) allowed us to deliver in-depth healthcare while at the same time improving the protection of health workers. The Optimized Standard of

Care Guidelines, reviewed in January 2019, clearly define the necessary standards of care, including fluid resuscitation, electrolyte monitoring and correction, treatment of potential co-infections, nutrition and the management of complications.²

To meet these standards, ETCs also need adequate numbers of trained staff and sufficient and appropriate medical equipment. While the CUBE helps address protection from contamination, dedicated resources, staff with specific biosecurity training and clear protocols also have to be in place. Local recruitment, training and engagement of Ebola survivors is also necessary if the standards are to be met.

Box 1: The CUBE (Biosecure Emergency Chamber for Epidemics)

Drawing on lessons learned in the aftermath of the Ebola outbreak in West Africa in 2014–2016, ALIMA and its partner, Securitec, developed the CUBE, a self-contained and easily transportable system for use in outbreaks of highly infectious disease.

The CUBE’s main advantage is that it provides intensive and resuscitation care in a more secure area for health workers, with the patient at the centre. Transparent walls and external arm entries mean that medical teams can continuously monitor patients, checking vital signs, administering solutes and adapting treatments, all while reducing the risk of contamination. The transparent walls allow patients to remain in contact with the outside world, including family members, without risk of contamination.

¹ See <http://apps.who.int/ebola/ebola-situation-reports>

² WHO, *Soins de support optimisés pour la maladie à virus Ebola – Procédures de gestion clinique standard*, 2019.



Kalunguta Integrated Transit Center, these two 'garde-malades' are two Ebola patients discharged as cured from the Katwa Ebola Treatment Center

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New treatments and clinical research

In addition to the Optimized Standard of Care, four drugs have been used to treat Ebola patients under the MEURI protocol (Monitored Emergency Use of Unregistered and Investigational Interventions). MEURI is an ethical protocol designed to evaluate the potential use of experimental drugs during public health emergencies. It was initiated by the World Health Organization (WHO) after the West African outbreak.³

Because it was not clear which drug was most effective, a randomised controlled trial was conducted between November 2018 and August 2019 by the PALM Research Consortium. The preliminary results strongly indicated that patients receiving either mAb114 or REGN-EB3 had better chances of survival than those taking the other two drugs.⁴

While the results of the trial have helped increase survival rates, it is important to continue innovating to improve care. One key priority is finding better ways to manage critical renal failure, a common cause of death among Ebola patients. Clinical research implemented immediately at the beginning

of an outbreak should also continue to improve treatment efficacy and increase knowledge of infectious pathogens.

Integration of clinical standards of care

Providing optimised care for Ebola patients should not mean neglecting the existing health system. To avoid this risk, ETCs should be set up within existing health facilities. ALIMA has established two of the ETCs it operates within the compounds of the general hospitals in Beni and Mambasa. Integrating ETCs into existing health structures reinforces national health systems, strengthens the training of public health workers, who make up the majority of treatment centre staff, and expands the pool of expertise. It also helps ensure continuity of care for people who do not test positive for Ebola. For example, several pregnant women admitted as suspected Ebola cases at the ETCs were given a safe emergency cesarean section, before being referred to the maternity ward for post-operative monitoring and neonatal care.

Mortality cannot be reduced without proper outreach and decentralised care to minimise the time between the onset of symptoms and admission to a treatment centre. However, the low chances of survival and the isolation of the ETCs and of the patients within them spread rumours and fear. This makes people delay going to or refusing referral to an ETC. Any delay in treatment is associated with higher mortality. The PALM study in DRC shows that 'the odds of death increased by 11%

³ WHO, *Consultation on Monitored Emergency Use of Unregistered and Investigational Interventions for Ebola Virus Disease (EVD)*, 17 May 2018.

⁴ Palm Consortium Study Team, 'A Randomized, Controlled Trial of Ebola Virus Disease Therapeutics', *New England Journal of Medicine*, 27 November 2019.

for each day after the onset of symptoms that the patient did not present to the treatment center’.

Individual, targeted and patient-centred health promotion

Community mobilisation must be centred on the patient, meaning that family, friends and any other contacts around a confirmed patient must be considered as patients as well. They are under high levels of stress, and face a high risk of becoming sick and dying if proper action isn’t taken. They have to be monitored individually, with their own issues and characteristics.

Current approaches to community mobilisation in North Kivu do not respect privacy and local dynamics. As such they are unproductive in reducing delays in admissions. In the same way, wide case definitions may have a positive effect on case detection, but are not adapted to the community. Community mobilisation must be understood as a pull factor to help each individual, ensuring their own follow-up and acting as leaders for others. Arranging visits to ETCs for families, specific community groups and community leaders can be effective in this regard, alongside measures to make monitoring contacts more acceptable. While it may be tempting to use communications experts to disseminate messaging around Ebola, it is essential that this communication is carried out by communities, families and friends, and through influential community leaders; religious leaders, for example, cannot become health agents for the Ebola response, but they will be able to pass on the right messages. Leaders understand local, traditional dynamics, and know what messages will have the greatest impact much better than external actors.

Integrated and decentralised transit centres

Integrated Transit Centres (ITCs) implemented in previous outbreaks were used again in North Kivu. Under the ITC model, part of the responsibility for case management is integrated into the local health system. The aim is to enable local health workers to manage suspected cases, while maintaining healthcare provision that is adapted to the needs of the community. The approach brings the management of suspected cases closer to communities, within a structure and with health personnel that people know. As an example, the first ITC we set up in the Hospital Centre Sainte Famille in Mukuna is now managing suspected Ebola cases in a six-bed unit, with no external support. After two or three months’ training and supervision, the unit is being managed by hospital health workers.

While ITCs manage suspected cases, case detection will be improved only if the hosting facility provides a wide range of healthcare. Access to standard healthcare creates a pull factor, enabling coverage of a large number of patients. With triage at admission, any sick people fitting the Ebola case definition can be admitted for testing and case management. Referral is faster, breaking the transmission chain, reducing isolation

times and decreasing the risk of mortality. This approach also helps support wider health facilities and limit increases in mortality linked to other diseases.

Comprehensive care for Ebola survivors

As of 10 January 2020, there were 1,122 Ebola survivors in North Kivu and Ituri. We know three things about Ebola survivors. First, most patients discharged as cured from ETCs present symptoms or conditions caused by the disease. They enter a chronic phase of the disease, after the critical phase managed within the ETC. The most common problems are musculoskeletal pain (50–70%), ophthalmological disorders, abdominal pain, headaches, asthenia, memory and hearing loss and psychiatric problems. According to a cohort study in Guinea, within a year after discharge from an ETC, Ebola survivors were five times more likely to die than other Guineans.⁵

Regular medical follow-up is essential to ensure that the after-effects of Ebola are managed in a timely manner immediately after discharge from an ETC. Health services have to be offered close to patients, by a multidisciplinary team combining all the monitoring axes. Primary- and secondary-level health structures should be supplied with appropriate drugs and equipment, both for routine check-ups and specialised consultations, and additional training for health personnel must be ensured, as well as training in biological monitoring for laboratory technicians. Where there are complications, referrals should follow the classic health pyramid to offer specialised care to patients.

The high risk of psychological disorders among patients who have recovered from Ebola in a treatment unit requires proper follow-up. Reported psychological problems include anxiety, depression, sleep disorders and neuropsychiatric manifestations. Other signs, such as erectile dysfunction, amenorrhea and decreased libido, have also been reported. Patients discharged from an ETC should receive psychological support, cognitive-behavioural therapy, family therapy and psychoeducation.

Affected individuals and the families and relatives of cured or deceased patients may also report psychosocial disorders, and these will need to be managed. Healed and affected people may also face social stigmatisation, including exclusion from the community. The main problems faced by survivors at the socio-economic level are job losses, with a particular increase in vulnerability among women and young people in families where a family member has died from Ebola. There is thus a need for social support to reduce stigma and socio-economic vulnerability among these groups.

5 Mory Keita et al., ‘Subsequent Mortality in Survivors of Ebola Disease in Guinea: A Nationwide Retrospective Cohort Study’, *Lancet Infectious Disease*, 19:1,202–08, 4 September 2019.

Integration of chronic Ebola care within the health system

At this stage, where medical research is not as far advanced as clinical trials for therapies or vaccinations, the strongest certainty is that patients discharged as cured from an ETC will require medical management to decrease the risk of death and increase the chances of reintegration. This follow-up resembles outpatient treatment and must therefore be integrated within the health system as with any other chronic disease.

We cannot expect to reduce mortality from Ebola without responding to an outbreak through a patient-centred approach. Otherwise, the best we can hope for is to limit the spread of new cases. ALIMA believes that proper clinical management of an Ebola patient starts from the day a case is confirmed to the day where the viral load equals zero and there are no more symptoms, which might take several years. Improvements have been made in the clinical management of confirmed cases, but the delay between the onset of symptoms and admission at a treatment unit remains the main risk of death. To reduce this

delay, more responsibility must be given to the community and local actors.

Finally, medical research must continue, and should focus on innovative solutions. For example, a rapid diagnostic test would reduce the time between admission and diagnosis from two days to a few hours, buying precious time to start treatment. It would also help in avoiding the referral of non-confirmed cases to an ETC and contribute to better clinical management for non-Ebola cases. Early diagnosis might also prevent a contact person falling sick by delivering a prophylaxis post-exposure, based on the two drugs that have been shown to reduce mortality among confirmed patients.

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Community first: the key to stopping the Ebola epidemic

Marcela Ascuntar

The tenth Ebola outbreak in eastern Democratic Republic of Congo (DRC) was declared in August 2018. Nineteen months later, it has resulted in over 3,400 confirmed and probable cases and more than 2,200 deaths. By October 2019, the head of the Ebola response, Dr. Jean-Jacques Muyembe, and the Congolese government in Kinshasa were predicting that the outbreak would come to an end before the year was out. They had good reasons for this optimism: the caseload had fallen to an average of eight a week in the first three weeks of November – a sharp decline on the 112 cases or so a week at the peak of the outbreak in May 2019. Transmission had been confined to a small set of four neighbouring health zones. An air of hope prevailed among response actors.

Serious security incidents targeting response teams in late November 2019 had an impact on the progress made over the past months. Security challenges led to epidemiological hurdles because of the reintroduction of the virus in urban centres that had previously been cleared. Additionally, a survivor who was working for the response suffered a relapse of the virus in December 2019, directly infecting over 30 people. Although relapses are rare, epidemiological experts have expressed their concerns about this and other similar cases, in terms of the increased severity of the virus in the survivor's body. Response efforts are being reinforced to get back on track to beat the epidemic and stop transmission.

Resistance

The Ebola outbreak in DRC is the second largest the world has seen and the first in an active conflict zone. One of the main challenges from the outset of the response was the local population's resistance to health workers, response partners (including NGOs) and the response itself. In the early months of the epidemic, the response focused mainly on medical treatment and primary care. It was essential to ensure that local health structures effectively treated patients to prevent the spread of the virus. However, a top-down structure and messaging and response activities that were not adapted to the local context and traditions meant that communities felt alienated from decision-making, leading to mistrust and increased resistance in an area where decades of conflict had already instilled mistrust in the government, its armed forces and international actors. These conditions served as a breeding ground for rumours and false information during the first part of the response.

Analysis of community feedback has revealed key issues in the response, including lack of harmonisation or consistency in messaging, which was also at times too vague or technical; mistaken or non-existent translation into local languages; and a militaristic approach involving the use of armed escorts to access Ebola-affected areas. As an example, Safe and Dignified Burials (SDB) put in place to avoid further contamination

created tensions between the response and local communities in the early months. While this procedure is efficient and well-known to health practitioners, SDB teams initially did not take into account local customs or cultural practices, such as how, in some areas, only men should carry the deceased's body. After teams collected and analysed feedback, they recruited all-male SDB teams to address community concerns. Other procedures have also been adapted, such as using body bags with clear plastic windows instead of all-black bags so that relatives can see their loved one as they are laid to rest.

The early months of the response also coincided with a contentious period in Congolese politics. Delayed presidential elections, the suspension of voting in Ebola-affected areas and ongoing violence contributed to the politicisation of the response and increased popular skepticism as Ebola was perceived as a 'political tool' to interrupt the elections and prevent people from voting. In 2019, the World Health Organization (WHO) documented an estimated 390 attacks on health facilities in DRC, killing 11 health workers and injuring 83 healthcare workers and patients.¹ A third of these incidents were acts of resistance to the response.

A system-wide scale-up

Based on community feedback and the duration of the outbreak, it became evident that a health response alone was not a sustainable approach; instead, an approach that was more attuned to community needs and adapted to the local context was required. In late May 2019, a system-wide scale-up of the Ebola response was declared that adopted a more community-centred approach. Advocacy and coordination work by a group of INGOs, including Mercy Corps, played an important role in this overhaul. Several INGO meetings were held to agree on harmonising community engagement across interventions, and integrating anthropological research such as that carried out by the UNICEF Social Science Research Group (SSRG).

A community-centred approach

Under the scale-up, addressing the most pressing humanitarian and social issues facing affected communities and improving access to essential services became response priorities. However, there are still some challenges: while organisations are increasingly collecting feedback from communities, few are perceptibly adapting their activities, and more advocacy is needed within the response for different strategies that could adapt response activities to meet local concerns. To address this issue, Mercy Corps and other response actors have been implementing community engagement approaches in line with the Community Engagement Commission led by the Congolese Ministry of Health and UNICEF. Risk communication

and community engagement work needs to continue even after the epidemic ends, as a means of helping communities develop their own strategies to fight the current outbreak and prevent future ones, and to help people recover from this outbreak's social and economic impacts.

Mercy Corps has also expanded its work in Ebola response areas to address community needs around basic services, including access to water. With funding from OFDA and the UN's DRC Humanitarian Fund, Mercy Corps is repairing existing water infrastructure and drilling new wells, helping to ensure that local communities have access to clean water – a benefit that not only supports Ebola prevention efforts, but also addresses a critical local need. Communities actively participate by identifying and expressing their needs via consultations and focus groups, and by creating community action plans. Local workers are employed on construction sites on a cash-for-work basis, and communities elect committees responsible for construction and repair work.

Information is critical

Effective community engagement and mobilisation also means that information about Ebola comes not only from medical staff, international organisations or the government, but also from community leaders and individuals recognised and trusted by their community. By taking into account community dynamics, we lay the groundwork for a more decentralised response and better communication flows. Mercy Corps has used evidence from the West Africa Ebola response in 2014–2016 to demonstrate how critical a role community mobilisation plays in curbing an outbreak.²

As part of Mercy Corps' response to Ebola, the ECHO-funded programme 'Pamoja' ('together' in Swahili) established 40 information centres in Ebola-affected areas. The centres are managed by local organisations trained and supported by Mercy Corps, with key information on the disease, good sanitation and hygiene practices and prevention measures and how to react should symptoms appear. The sooner a case is detected and addressed, the shorter the chain of contamination. As the local population receives the information directly from local and community-recognised organisations, a domino effect helps spread good practices in the community, and fight disinformation.

These centres not only provide information to the community, but also gather feedback about response actions and teams. By analysing this feedback, Mercy Corps and Ebola response teams intend to adapt and adjust their activities to address rumours and disinformation, improve programmes and provide useful information to the broader humanitarian community. Some of the most common rumours the centres have received and

1 T. Ghebreyesus, 'Ebola Responders Face Deadly Attacks', *The Guardian*, 10 December 2019.

2 *Community Mobilization: Essential for Stopping the Spread of Ebola*, Mercy Corps, 29 May 2019.



October 2018, North Kivu, DR Congo. Martine Kavucho, 30, shows her daughter Christine Botulu, 6, the handwashing techniques she learned at the health centre as part of Mercy Corps' Ebola response.

© Rudy Nkombo for Mercy Corps

clarified are the belief that Ebola was invented by the government as a way of annulling the presidential elections, or was created so that foreigners could make money from it. Misinformation on possible side-effects of the two vaccines is also common: in early January 2020, one centre picked up a rumour about one of the Ebola vaccines affecting women's fertility. In response, thanks to a cascaded sensitisation campaign, 67 people in Butembo were persuaded to get the vaccine.

Coordination is key

A coordinated response and clear information-sharing among NGOs, UN agencies and government institutions is essential in any response, but particularly so in an Ebola crisis, where a fast and effective response is necessary to stop transmission. Conversely, a lack of coordination between responding actors can lead to the duplication of structures and activities.

Thanks to adjustments within the response plan, important reforms in the government coordination structure³ and a

strengthened coordination and support mechanism following the declaration of the system-wide scale-up in May, coordination has improved. NGOs were given a voice in strategic coordination forums, the Ebola Emergency Response Coordinator (EERC) appointed by the UN Secretary-General began to call meetings exclusively with NGOs and the Social Sciences Research Group reinforced its direct support to technical commissions with an emphasis on anthropological findings.

Building resilience to future outbreaks

Community resilience to future outbreaks can only be built by reinforcing existing structures such as local organisations and traditional community leadership, and Mercy Corps ensures that traditional and/or religious leaders are included in the engagement process (via local organisations, community structures such as Community Action Cells (CACs) or voluntary Care Groups). Mercy Corps has used community feedback to shape future programming, and will continue to give a central role to pre-existing community structures.

Due to high population mobility, not least in response to conflict, efforts to address Ebola must remain consistent, and response capacities should be maintained in high-risk areas

³ In the second half of 2019, the government of DRC appointed Dr. Muyembe, a well-known researcher who specialises in Ebola, as the head of the Multisectoral Committee for Ebola response reporting directly to the National President Tshisekedi.

until the epidemic is over, even where Ebola seems to be under control. In late 2019, the government began holding high-level discussions on the post-Ebola transition, and the most recent Strategic Response Plan has integrated priorities to support the health response, including the response to needs beyond Ebola, such as access to essential services in health, education and water and sanitation. The post-Ebola transition plan is centred around three key areas: strengthening health systems for this and any future epidemics; a multi-sectoral approach to address other basic needs; and contributing to local stabilisation, social cohesion and governance to link emergency and development phases.

As the post-Ebola phase approaches, we must also consider the survivors and their families. More needs to be done to support the 1,000-plus survivors to overcome stigma, as well as help with their social reintegration. Mercy Corps is designing

a post-Ebola strategy that includes early recovery, such as providing livelihood support to families affected by Ebola and capacity-building of local organisations. Mercy Corps' current and future programming puts a particular focus on three main intervention areas (Butembo, Beni and Katwa), which have been most affected by the outbreak, and which account for 72% of survivors. The post-Ebola strategy currently being drafted in Kinshasa should be realistic and respond to the main concerns identified via community feedback. Mercy Corps, together with other INGOs, is currently advocating for two additional seats for INGOs in national exit strategy discussions. As this crisis has demonstrated, community engagement that goes hand-in-hand with coordination is a fundamental factor in successfully fighting this disease.

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Lessons not learnt? Faith leaders and faith-based organisations in the DRC Ebola response

Bernard Balibuno, Emanuel Mbuna Badijonga and Howard Mollett

The response team did not understand how we live here. They arrived in villages in biohazard suits, looking like members of armed groups and frightening the population. Without explanation, they would demand to take the patient away. ... The team did not build a dialogue, taking into account local cultural values. In Butembo, the rumours were that the Ebola response teams were the origin of the outbreak, rather than the solution. Priests worked hard to change this false belief. Monsignor Sikuli Paluku Melchisédech, Catholic Bishop of Beni-Butembo (September 2019)

Local faith-based organisations (FBOs) and faith leaders played important roles in the Ebola response in DRC. Unfortunately, however, the international and national response was slow to recognise their contribution. Funding and decision-making on the response centred on UN and host government leadership and scaling up the medical response, without adequate attention to community engagement. All this played out in a context of violent conflict between the central government, local political actors and armed groups in affected areas, which spread and shaped rumours about the virus and the response. As a consequence, opportunities to address the fears people had about Ebola and the response to it were missed. Backlash against the Ebola response grew and, tragically, lives were lost – both frontline aid workers and community members who did not receive the information and support they needed from sources they trusted. As such, the Ebola response in DRC illustrates wider challenges in efforts to localise humanitarian action and meaningfully engage communities in a crisis response.

The contribution of FBOs and faith leaders to the response

It is hard to overstate the importance of faith and the roles played by faith institutions across DRC; an estimated 60% of educational facilities are managed by faith groups, and Catholic health structures ('Bureau Diocésain des Auvres Médicales') manage 40% of the health system. As a consequence, faith groups were involved in the Ebola response from the outset. Catholic health facilities reported cases of people dying from a sickness involving bleeding in Mabalako in May 2018, but a strike in the public health system meant that cases were officially registered only in July, with the formal crisis declaration coming in August.

Faith groups were involved in the Ebola response from the outset:

- *Preaching by example* – for example, religious leaders played important roles in countering rumours and misinformation. Over 70 religious leaders had themselves publicly vaccinated in Mususa district to demonstrate by example that rumours against the vaccine were false. The Catholic bishops' 'Ebola Free Families Campaign' mobilised grassroots women's and youth groups in parishes to meet in neighbours' homes and talk through misunderstandings surrounding Ebola, the vaccine and the wider response, as well as address the stigma faced by Ebola survivors. Muslim and Eglise de Reveil leaders undertook similar activities.
- *Modifying religious practices* – behaviour change is a critical part of community engagement in an Ebola

response. To that end, faith groups developed and disseminated guidance through parishes and other prayer structures on washing hands before distributing communion and after conducting offertory collections, 'taking communion by hand, and no longer directly in the mouth' and establishing chlorinated water points at places of worship. Priests were trained at diocese level, and passed this training on to parishes (Shirika) and community groups.

- *Religious institutions as centres for refuge and assistance* – building on other basic forms of assistance provided at religious institutions, faith groups established reception areas and areas where people could be referred on to Ebola treatment facilities, provided hygiene facilities such as handwashing kits, supported monitoring of case contacts through food distribution and psychological assistance, and established early warning groups in schools.
- *Playing an intermediary role between the wider response and communities* – as the backlash grew against the response by the government and international agencies, religious leaders played crucial intermediary and advocacy roles. Local communities resented the disparity between the international resources poured into addressing a health crisis with international

ramifications, and the inadequate action taken to tackle national, regional and global drivers of the violence they face every day. Faith leaders have called on the government and international agencies to develop, implement and support community resilience plans to integrate recovery from Ebola alongside wider plans to address intersecting humanitarian, governance and conflict risks in affected areas. Local FBOs and religious leaders in those communities can contribute to work on conflict and governance issues, but efforts on this front must be based on a careful analysis of conflict dynamics, the risks faced by local faith actors and the various ways different actors – government, UN, INGO, FBO – are perceived by local communities and armed actors.

Challenges in engaging with the response

In every strategic meeting on the crisis, faith-based organisations were mentioned as one of the major actors in the response. Unfortunately, this point was made without faith actors actually being invited to those same meetings. National FBO manager, Eastern DRC, February 2020



Women listen to a talk about Ebola in a mosque in Goma DRC

© Tommy Trenchard/CAFOD

Many of the challenges FBOs and faith leaders faced in engaging with the wider response in DRC had precedents in previous Ebola responses. A study by CAFOD and other FBOs of the 2014–2015 Ebola response in West Africa found that:

*an essential element was the need to mobilise communities to change behaviour and in many cases neither health staff nor the government were well placed to do this. Instead, the local community itself was best placed to effect change, and faith leaders, as trusted and respected members of communities, played an important role as agents of social change.*¹

In DRC, government and international staff deployed to the response did not come from the affected areas, did not speak local languages and brought with them practices that ran counter to local cultural norms (for instance regarding the feeding of patients and burial practices). One UN staffer, who had also been involved in the West Africa response, pointed to the lack of interest in learning from the response in Sierra Leone: ‘I was literally told “This is not West Africa. End of story.” Of course, nobody thinks you can cut-and-paste, but the UN failed to learn even the most basic lessons or apply them in DRC’.²

Challenges with coordination and decision-making

A lot of this response was led by doctors, who are trained to hone in on a medical problem. The culture of standing back and looking at the bigger picture was not there.
INGO staffer, February 2020

The challenges FBOs and faith leaders faced in engaging with the Ebola response reflect in part wider challenges with the overall leadership and coordination of the response, which emphasised the medical dimension and neglected the importance of community engagement.

The initial response centred on bolstering health clinics at the epicentre of the crisis, which entailed deploying Ministry of Health (MoH), World Health Organization (WHO) and NGO staff to these areas. As one FBO staffer put it to us: ‘From the outset, it felt very much a command and control approach with a focus on the medical aspect, whereas attention to community sensitisation came much later’. The then Minister of Health centralised control of the response in the central line ministry and increased MoH staff in Kinshasa, and WHO staff were deployed from across West Africa: for one FBO staffer, ‘Those of us working at the local level felt disconnected from decision-making, out of the inner circle involved, and marginalised from the response’. Lack of engagement with FBOs reflected a wider

scepticism at the MoH about the role of civil society, especially in Eastern DRC. One UN official observed that:

WHO could have done more to encourage the MoH to value and support the contribution of civil society, including FBOs. This problem was obviously all the more acute because the crisis had broke out in opposition-controlled areas in Eastern DRC. What’s more, when staff are deployed from Kinshasa on \$150 per-diems, there’s a real disincentive to localising the response.

While IFRC and UNICEF tried to gather the views of local communities, ‘These were largely ignored by the leadership of the response’.³

To help local FBOs and faith leaders reflect on their response and engage with others, international FBOs – including CAFOD, Tearfund, Trocaire, Misereor and Cordaid – supported their local partners to convene a series of workshops with FBOs and faith communities in Ebola-affected areas. Over 120 religious and community leaders gathered in four zones (Goma, Bukavu, Bunia and Butembo) between 28 August and 14 September 2019 to reflect on good practices and challenges in their work, and identify recommendations to inform the wider response.⁴ Steps were taken to include diverse faith communities and enable Ecumenical and inter-faith exchange, including Muslim and indigenous faiths.

These roundtables also recognised the need for faith actors to get their own house in order, including by strengthening provincial coordination among faith groups. FBOs and faith leaders had an established inter-faith working-group in Kinshasa, including sub-groups on health and other issues, but there is no such structure in Goma or in other cities and cooperation at sub-national level has been more ad hoc. Moves to roll out a community engagement structure at the local level (the Cellules d’Animation Communautaire (CAC)) have helped clarify guidance on, and scale up, community mobilisation, but this work only began more than a year after the crisis was declared. One informant asked ‘why create a projectised structure with a grant facility, rather than look at the structures which already exist in these places, which have legitimacy, and engage with and support those?’.⁵

Participants also recognised the need for a more structured and consistent approach to the advice technical specialists give church leaders as new issues arise, and more practical and systematic engagement in the wider coordination of crisis

1 CAFOD, Christian Aid, Tearfund and Islamic Relief, *Keeping the Faith: The Role of Faith Leaders in the Ebola Response*, 2015 (<https://cafod.org.uk/News/Press-office/Press-releases/Faith-leaders-Ebola-virus>).

2 Interview, February 2020.

3 Interview, February 2020.

4 Faith groups attending the roundtables included the Awakening Churches of the Congo (ERC); the Adventist Church; the Neo-Apostolic Church; the Kimbanguist Church; the Union of Independent Churches of the Congo (UEIC); the Church of Christ in Congo (ECC); the Catholic Church; the Anglican Church; the Islamic Community of the Congo (COMICO); the Salvation Army; and the Orthodox Church.

5 Interview, February 2020.

response efforts in DRC. At the national level, this could involve reviewing how the Kinshasa inter-faith working group relates to the Humanitarian Coordinator, Humanitarian Country Team and the clusters in planning, funding and accountability efforts.

Challenges in funding and programme partnerships

It should be obvious that a response to Ebola requires engagement with priests, pastors and parishoners. If someone is sick, then it is through this kind of community structure, which has their trust and that of their family, that support can be provided. It also gives people a sense of control over what's happening to them. UN official, February 2020

FBOs and faith leaders faced significant difficulties accessing timely and adequate funding. This was in large part a result of the centralised approach of the government, donors and the UN, and inadequate progress on localisation. As one staff member from an FBO put it: 'One UN official asked us, what do the Christian NGOs need funding for? You already have people on the ground everywhere. Shouldn't they just be doing this anyway?'.⁶

Under the wider coordination structure, leadership for community engagement lay with UNICEF and donor funding was largely channelled there. Some FBOs with pre-existing partnership cooperation agreements (PCAs) with UNICEF were able to negotiate funding; Norwegian Church Aid, for example, had ongoing programming on water/sanitation and gender-based violence, which tackled issues including hygiene and community sensitisation, and these programmes were adapted to address Ebola. For agencies without a PCA, UNICEF's modalities for partnership and funding do not permit much leeway or amendments to programming, though UNICEF has recently undertaken to review its approach to partnerships and flexible, multi-year funding.

The organisational model of some FBOs, which centres on fundraising from private donors in their religious community, means they often have less well-established relationships with the UN agencies serving as the conduit for institutional donor funding. In contrast to the technical and sectoral ways that UN agencies demarcate their mandates, FBOs tend to emphasise a holistic, multi-sectoral approach. Bridging these gaps is key to enabling more timely and responsive ways to fund their work. There are precedents for innovative consortia in DRC that have supported cooperation between FBOs and other humanitarian actors; the Shifting the Power consortium, for example, has helped catalyse cooperation to develop a new country-level NGO funding mechanism linked to the START network.⁷ But the

reality was that many FBOs and religious institutions resourced their Ebola response largely from their own funds.

Conclusions

We will still be here when this crisis is over, when there will still be much work to do in rebuilding communities devastated by Ebola. National and international bodies need to acknowledge, support and work alongside us.
Catholic Bishop of Goma, Willy Ngumbi

In DRC, faith is a central part of people's lives, religious leaders are trusted and respected, and Church structures have a presence across the country, including in areas where others do not. As such, engaging with FBOs and religious leaders should be an integral part, not just of the Ebola response, but also longer-term humanitarian, development and conflict efforts. The consequences of not doing so were already known from previous Ebola responses, but those lessons were not learned or applied in DRC. Change will only come through wider, concerted action on localisation and participation by affected communities, both in DRC and within the wider humanitarian system. To ensure that local faith groups, and people in crisis-affected communities, can exercise their agency and voice in this, a more politically informed approach is needed by donors, UN agencies and INGOs. Short-term, inflexible grants, where FBOs are contracted to deliver on priorities set by others, will not build trust or encourage learning. On health, education, community engagement and a host of other issues, more effective cooperation between FBOs and others can only emerge through longer-term partnerships. A politically informed approach also entails recognising the complex ways in which different actors – government, UN, INGO, local civil society, faith actors – are perceived by affected communities in conflict settings across the country, and what this entails for their ability to work safely and effectively. Otherwise, 'engaging faith leaders and communities' will remain lip-service, while all the financial, institutional and other drivers continue to push in the other direction.

In sum, priorities of relevance to Ebola response, both in DRC but also globally, include:

- Recognise the importance of community engagement from the outset of an Ebola outbreak and other public health crises, and the contribution of faith actors, alongside medical interventions.
- Embed Ebola recovery into a wider strategy addressing the conflict and governance challenges faced by affected communities.
- Establish practical entry-points for FBOs to participate meaningfully in coordination and decision-making on both Ebola response and recovery, and wider humanitarian, development and peace efforts at national and sub-national levels.
- Scale-up locally led funding, programming and partnership opportunities to build trust and practical

⁶ Interview, February 2020.

⁷ For more information on Shifting the Power, see: <https://startnetwork.org/resource/how-has-shifting-power-influenced-local-and-national-partners-response-emergencies>

cooperation between FBOs and other actors on emergency preparedness, response and resilience.

- Avoid instrumentalisation of faith leaders by international agencies looking to ‘win hearts and minds’ or gain access. Faith leaders should be engaged in a genuine dialogue, which would involve identifying shared or complementary agendas, as well as carefully

mitigating risks entailed for all involved – faith groups, UN bodies, local authorities and others.

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Grief and memorialisation: making meaning with Ebola-affected families

Theresa Jones, Noé Kasali and Olivia Tulloch

In order to prevent the spread of Ebola through the handling of dead bodies, burials are carried out by special teams who are trained to do this in a safe and dignified manner. This should be standard practice by response teams, and has been implemented in the North Kivu outbreak. A medically safe burial involves the use of body bags, disinfectant spray and personal protective equipment (PPE). Although safe and dignified burials (known as SDBs) were acknowledged as important in controlling the 2013–2016 West Africa Ebola response, the prescribed processes denied many families the chance to say goodbye in the way they would choose, and in line with their cultural values.

The consequences of this can be many, including resentment, anger, mistrust and fear (including fear of misfortune arising from not paying proper respect to the dead) and reduced access to the community support usually associated with traditional mourning practices.¹ This can appear as so-called ‘community resistance’ as people reject the actions of burial teams or the wider Ebola response. In the long term, when the natural human need for meaning, sense, knowledge, connection and ritual is denied, this can manifest in ongoing suffering, complicated grief and ‘ambiguous loss’, whereby an unclear loss without resolution halts the natural grieving process.² The powerful, natural support systems within family and community networks are easily unsettled in times of crisis, and this lack of understanding and social support from fellow community members presents a further impediment to healing.³ The Inter-Agency Standing Committee (IASC) lessons learnt for mental health and psychosocial support in the West Africa outbreak clearly state that: ‘the bereaved need to have the opportunity to mourn’. In cases where important funeral rites, mourning ceremonies and rituals are not allowed

in order to prevent and control infection, dignified and meaningful alternatives should be found.⁴

This has not always happened in the North Kivu outbreak. Early reports of community feedback by the International Federation of Red Cross and Red Crescent Societies (IFRC)⁵ indicated frequent delays between notification of a death and the arrival of burial teams: ‘Whilst the body is decomposing’, or teams not arriving at all. Reports suggested that burial teams frequently did not behave respectfully with families.⁶ Community feedback collected between August 2018 and May 2019 highlighted an overarching resentment that the Ebola response had not acknowledged the importance or magnitude of people’s grief. Families were feeling ignored: ‘To families who haven’t lost a loved one in this outbreak Ebola is a joke’.⁷

Analyses of community feedback data collected by IFRC have enabled responders within the Ministry of Health-led Ebola coordination structures to adjust and improve the response, and this has resulted in important improvements in feedback throughout 2019: ‘Before, the responders would hide the dead bodies, but today it’s good because they’ve just agreed to bury the dead where the family wants, thanks for that’. Additionally, the SDB Sub-Commission and Psychosocial Commission, which function as coordination mechanisms for thematic areas of the Ebola response, have worked to ensure that the funeral rites of specific ethnic groups, such as the Nande, are included in SDBs, so that families can be involved during the preparation of the body and during the burial itself.

4 IASC, *Mental Health and Psychosocial Support in Ebola Virus Disease Outbreaks: A Guide for Public Health Programme Planners* (Geneva: IASC, 2015).

5 The IFRC (with support from the Centers for Disease Control and Prevention (CDC)) has been collecting and analysing community feedback gathered from the National Society of the Red Cross since August 2018.

6 Social Science in Humanitarian Action Platform (SSHAP), *Social Science and Behavioural Data Compilation* (No. 3), *Ebola Outbreak Eastern DRC February–May 2019* (Oxford: SSHAP, 2019).

7 International Federation of the Red Cross (IFRC), *IFRC Community Feedback to Inform Ebola Response Efforts – July 5, 2019. Community Perspectives on Psychosocial Impacts and Suggestions for Addressing Them*, IFRC, 2019.

1 T. Van Bortel et al., ‘Psychosocial Effects of an Ebola Outbreak at Individual, Community and International Levels’, *Policy and Practice Bulletin of the World Health Organization*, 94, 2016.

2 P. Boss and J.R. Yeats, ‘Ambiguous Loss: A Complicated Type of Grief When Loved Ones Disappear’, *Bereavement Care*, 33, 2014.

3 Bortel et al., ‘Psychosocial Effects of an Ebola Outbreak’.



Managing a tree planting program in Masimbembe and Manzanabaza

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Informed by feedback data, locally recruited psychosocial agents provide bereaved families with psychosocial support. The Child Protection and Psycho-Social Support (CPPSS) strategy of the Psychosocial Commission (which is co-led by the Ministry of Health and UNICEF⁸) has sought to respond to the specific needs of confirmed and suspect cases of Ebola and their family members. The strategy outlines that affected families be followed up by a psychosocial agent and supported with material assistance such as a funeral kit (food assistance or cash) to contribute to the organisation of a subsequent ceremony. These efforts can at times be undermined, for instance if support takes too long to reach families, or only materialises after ‘community resistance’ has already begun.

Direct appeals to the IFRC include that families want to feel that deaths ‘mattered’ to response teams, including through more formal memorialisation of deceased loved ones. This suggests a need for more investment in community-based, contextually appropriate grief and memorialisation efforts. This would ideally involve local actors with the technical skills to guide families through such a process, and who are aware of the socio-cultural sensitivities and specificities of this work.

Case study: Bethesda support to grieving families

Bethesda is a local counselling organisation based in Beni, North Kivu. It is a faith-based organisation, but services are offered to all. Having operated in Beni and the surrounding areas since 2016, it expanded its services to meet needs relating to Ebola. Bethesda has documented families’ experience of Ebola deaths through community consultations, and has noted many negative experiences: ‘we were very angry as since we have been grieving, we have seen nobody coming here to comfort us, they were coming here often only to record’. Having identified a particular gap in support to families who have lost members to Ebola, Bethesda designed a process ‘to walk alongside grieving families in Beni and Mangina and provide care and healing in the aftermath of Ebola’. This involves guiding small groups of families through the stages outlined in Box 1, culminating in a memorialisation ceremony.

Feedback from families that have received support revealed several positive elements of the process. Many felt cared for and comforted: ‘the sessions have been the first time I have felt comforted, these sessions have helped me’. The value of remembrance was recognised, and specifically having a tangible symbol: ‘From this tree we will tell our girls and boys what happened in Masimbembe’; ‘This tree will help us to remember

8 Partners include the Danish Refugee Council (DRC), Alliance for International Medical Action (ALIMA), Division Provinciale des Affaires Sociales (DIVAS) and Division de l’Intérieur (DIVInter).

brothers, sisters and parents taken by the Ebola virus'; 'While planting my tree, I understood that this will make the situation I went through unforgettable. By eating the fruit from this tree, I will understand that, despite the situation, there can be a moment of joy. This tree represents a flower that I was supposed to plant on the grave of my mother'.

Box 1: Bethesda support process

Stage 1: Relationship-/trust-building

- *Introduce Bethesda* – what it is, and why it cares about grieving families
- *Communicate* a sense of honesty and humility
- *Invite* questions about Bethesda and its connection to the Ebola response
- *Describe* the support process to grieving families and discuss why such a process may or may not be important
- *Give* families a chance to participate if they wish to do so
- *Set* group boundaries for those who choose to take part
- *Discuss* questions regarding Ebola

Stage 2: Sharing stories and coping mechanisms

- *Discuss* the impact of Ebola on families, including stigma, shame and stress
- *Invite* families to describe one or two items that have personal significance or hold personal memories, which may have been destroyed through Ebola hygiene activities
- *Share* stories of loved ones who died
- *Write* or narrate a goodbye letter to their loved one
- *Share* strategies around individual/community coping mechanisms and skills. What are people doing now? Can they re-find old ways? What new or different ways may emerge?
- *Discuss* and practice approaches to relaxation and emotional regulation, and encourage participation in social activities within the community, such as prayer, songs and music

Stage 3: Memorialisation ceremony

- *Discuss* the importance of family and community support systems
- *Agree* strategies to support one another in future
- *Discuss* what a memorialisation ceremony is and what it means to the community
- *Agree* what the tree-/flower-planting or ceremony for memorialisation will look like: choose where, when, which trees and flowers (which Bethesda purchases) and how the ceremony will be organised

It was also clear that healing does not come from a single act or ritual, and that it takes time: 'Our healing will be connected to the growth of this tree'. One family member described the process of the Bethesda sessions: 'The first day I attended the group, there was a time when I felt like the session was touching my heart and directly to my personal issues. When we worked on the goodbye letter, this was the beginning of hope for me. This letter helped me so much and after completing it I felt so much better. The following day was Sunday, I went into my room and read the letter again. After the reading I again felt so comforted. I came to this last session with much joy within me'.

Lessons from self-reflection

In an effort to understand the impact of their work, the Bethesda team have identified several inter-related principles which are core to the success of their approach. First, being identified as neutral is important to avoid politicising the work, which has been a prominent issue in this outbreak. Many families report feeling safer engaging with Bethesda staff as they are not connected with the Ebola response and are already accepted as part of their community. This allows families to share and express themselves knowing that it won't bring 'trouble'. Related to this is the need to adopt a light-touch approach, being humble and sitting with people, without being linked with the expensive cars and equipment associated with the response. Not only does this draw less attention and protect the privacy of families, it also sends a message that Bethesda are there only to be with them, without other intentions.

Bethesda's approach depends on localised, cultural expertise, being familiar with the cultural customs of the area, while having technical support expertise. Families planted trees at the culmination of the process, as part of the memorialisation ceremony. In Nande culture, a 'mahero' is considered a secret place, a place of honour for those who have died. A tree planted to represent 'mahero' is believed to have both cultural and spiritual meaning, which has been central to the significance of the tree-planting ceremony. Bethesda also put emphasis on showing they care by spending time with families over a period of weeks without interruption, empathising with their pain and grief. Rather than focusing purely on rituals, as was the case in the West Africa outbreak, the Bethesda process aims to give space for genuine mourning.

The approach facilitates the supportive power of family and community: grieving families communicate a sense of togetherness as coping mechanisms are shared, new meanings are co-created and the foundation for ongoing practical and emotional support is laid. The sessions become a unique place to reconstruct, even on a small scale, the needed sense of community: 'Our life is also like this tree. As human beings we need the same things the tree needs in order to grow. I have learned the importance of being connected to the community around me'. Ultimately, Bethesda let the bereaved lead the process. This involves choosing to participate, deciding where

the family meetings should take place and what the ceremony of memorialisation will include – where, when and how it will happen, what food will be shared and what type of tree or flower will be planted.

The main challenge has been limited human and financial resources. When additional families presented themselves for sessions the Bethesda team felt ‘selecting and unloving’ when they could not include them. The team also could not offer longer-term support for family members with more extensive needs. The heavy emotional toll of the programme has meant that each facilitator requires a weekly debriefing session with a supervisor, and at least one day a week for rest and self-care.

Conclusions and recommendations

In current and future Ebola outbreaks, community-led memorialisation processes should be supported by government or other actors, to show solidarity with and compassion for families of Ebola victims, and be a positive action for the wider community. These actions should be chosen by affected

families themselves; for example, Bethesda-supported families suggested that processes could also include the construction of graves, with a cement or tile grave marker, as is customary within a year of a person’s death. Where opportunities lie out-side of formal response mechanisms, especially within grassroots structures, these must be encouraged and supported. Broader integration of this type of approach by other actors in the response would help overcome the challenge of limited human and financial resources.

The core principles identified through Bethesda’s process offer powerful lessons for all sectors of an Ebola response. Identifying as neutral; humility; cultural expertise; facilitating the supportive power of family and letting communities lead – all should be taken as standard considerations for a response that is effective and responsible.

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Replacing the language of fear: language and communication in DRC’s latest Ebola response

Ellie Kemp

We know that effective communication with communities at risk is essential to containing disease outbreaks. Yet people in the latest Ebola response in the Democratic Republic of Congo (DRC) can’t always access the information they need. Even if they can access it, they can’t always understand it. And even if they understand it, they don’t always trust it. Three factors currently limit the effectiveness of health communication in Beni, the town at the centre of the current outbreak:

- The language responders use.
- The content responders deliver.
- The way responders deliver it.

Local health communicators, who speak local languages and are aware of local sensitivities, have a vital role to play in making communication more effective. But they need better support and training to overcome the obstacles to effective community engagement.

These are the findings of a Translators without Borders study carried out in September 2019 with the International Rescue Committee (IRC). TWB conducted interviews and focus groups with more than 200 health communicators, patients and residents in different areas of Beni. Their responses should help to improve people’s understanding and acceptance of Ebola information in the current outbreak. The results should also inform preparedness for the next major disease outbreak.

Communities want information in the languages they speak and understand

Beni residents and even health communicators remain confused about aspects of Ebola and the Ebola response. This is partly because written communication is in French and Swahili, which only more educated people can read accurately. Health communicators told us they often speak Nande with women, particularly older women. Yet the information materials and training they base their communication on are in French and Swahili.

Beni residents speak at least seven languages; other affected areas of eastern DRC are similarly linguistically diverse. Swahili is a lingua franca in the east of the country, but that doesn’t make it an effective language in which to communicate about a deadly disease with people whose first language is Nande, Lingala or Mbuba.

The use of languages and concepts that people don’t fully understand breeds fear and suspicion. In Beni, the combination of a volatile security situation and an alarming disease has created a climate of fear and distrust. Most focus group participants told us that, at the start of the epidemic, they interpreted the use of languages they didn’t understand as a threat. Consequently, they thought Ebola was a weapon of war sent to kill them.

The terminology of the response encourages fear and confusion

Some of the French words commonly used in the Ebola response unintentionally encourage such suspicions. Study participants interpreted the warlike riposte (response, literally ‘fighting back’) as an attack or battle, and *vainqueur* (survivor, literally ‘winner’) as the victorious party. Earlier findings from the Social Sciences Research Group¹ raised similar concerns, but responding organisations have not generally changed these language habits.

Distrust discourages individuals from seeking treatment or acting on guidance about preventing the disease. Since the epidemic began, people feel they have been deprived of agency and freedom of choice. The fear of being taken to an Ebola treatment centre or locked in isolation against their will is immense. Health communicators explained that people associate words such as ‘ambulance’ and ‘isolation’ so strongly with death that it is best to avoid using them. Local residents told us the fact medical staff don’t speak their language compounds their concerns: they worry that misunderstandings might result in their being misdiagnosed with Ebola.

Confusion about aspects of Ebola is also linked to the use of specific medical terminology. Responders often use technical terms in French, even when speaking Swahili or Nande. We found that Beni residents misunderstand seemingly simple medical terms in French, like ‘allergic’, ‘virus’ or ‘molecule’. The adoption of English terminology such as ‘swab’ or ‘ring vaccination’ in French multiplies the confusion.

Health communicators identified abbreviations as another common source of confusion. Responders commonly use ‘ETC’ (in French ‘CTE’) for Ebola treatment centre, ‘TC’ for transit centre and ‘EDS’ as the French abbreviation for safe and dignified burials as a convenient shorthand. But their meaning is not always clear to communities, especially when an English or French abbreviation is used in a sentence in Swahili.

Some expressions related to the response are confusing because they suggest different meanings in the local context. The French *cas* (‘case’) is phonetically similar to the Nande diminutive *ka*; the word *suspect* (in English ‘suspected’) is associated with crime. Nande speakers interviewed accordingly understood *cas suspect* (‘suspected case’) as meaning a criminal of little worth, and were reluctant to be labelled as such. Similarly, ‘contact’ is used for everything from lists of telephone numbers to sexual relations. Even health workers were confused by its meaning in the context of the response.

Women are particularly vulnerable to misunderstanding when communication is unclear. Women are the primary caregivers when someone falls sick, and often the ones to take family



BA community outreach worker at a health facility in Beni, North Kivu, DRC.

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members to the health centre. But they are also less likely than men to have completed basic schooling. As a result, their understanding of French terminology, posters in Swahili and basic health information is often limited. Many described not seeking professional care for fear of misunderstandings that could result in misdiagnosis.

Health communicators lack support to translate key concepts

Health communicators struggle to relay critical Ebola information to at-risk communities in ways they understand and accept. They translate unfamiliar concepts from French into local languages in a context of generally low health literacy, and currently without guidance. Many do this with limited understanding of these concepts: study participants called for refresher training on key aspects of Ebola and the response.

Health communicators must also translate blunt or alarming terminology into wording that people won’t reject as disrespectful or distressing. People commonly associate certain words used in the Ebola response with death, and react negatively to them.

1 Groupe de Recherche en Sciences Sociales, ‘Note d’information - Perceptions des mots et langage de la riposte’ (Goma: GRSS, 2019).

Health communicators interviewed had developed alternative phrases for highly stigmatised terms such as ‘isolation’, ‘suspected case’ and ‘Ebola treatment centre’. These alternatives take a patient-centred perspective. They replace concepts of treatment (something the doctor does to the patient) with concepts of healing (in which the patient is the subject not the object). They refer to ‘patients’ rather than ‘cases’. They also offer simple explanations of technical concepts. For instance, one Swahili explanation of contact tracing literally translates as ‘monitoring of all people who have been close to a sick person’.

The result is to humanise technical concepts and make them less frightening and more accessible to community members. Responding organisations can learn from such examples. In the absence of guidance, however, each communicator develops their own explanations. These vary between individuals, and can introduce inaccuracy. For instance, one Nande explanation for Ebola treatment centre was ‘the place where there is healing’. While positive, this could suggest that all patients there are cured.

The combination of patchy understanding, unsupported translation and individual choices of euphemism results in inconsistency and contradiction. Local health communicators understand the local language and local sensitivities, and so find more respectful and acceptable explanations of key concepts. However, they lack a reliable understanding of those concepts in the French original, and support to ensure their translations don’t introduce unintended error and confusion.

Communities want information that meets their changing needs

As the Ebola response evolves, changes in policy and practice raise legitimate questions and doubts. New information seems to contradict what was said before. Communities want explanations, yet often communicators don’t have that information; they simply have new instructions.

Focus groups described the negative impact of a failure to provide credible answers and positive messages on relations with community members. Health communicators voiced distress at the resulting breakdown in trust.

Study participants voiced frustration with information like ‘You have to go early to the Ebola treatment centre to be cured’. They want a more detailed and sophisticated explanation of how the treatment drugs work, and why they were selected. They want to understand why pregnant women are now eligible for vaccination, whereas previously they weren’t. People want details on complex issues to inform their decisions, and they want them presented in what they referred to as ‘community language’ – meaning in a language and style they understand, using words and concepts they are familiar with.

There are positive moves to equip health communicators to provide such answers more effectively. In late 2019, members of the Risk Communication and Community Engagement Partners group developed plain French answers to common community questions. These will be most helpful if they are regularly updated, expanded to provide still more specific answers and made available to all local health communicators.

Study participants also called for more positive messages, recognising the greatly reduced infection rates over time. They are tired of hearing only about the risks, and want reassurance that the end of the outbreak is in sight.

Communities want information delivered in an appropriate and accessible way

How communicators relay information affects how accurately people understand it and how firmly they believe it. Local people and local leaders are more likely to be trusted messengers. Study participants prefer face-to-face communication, where they can ask questions directly. But they also considered various communication tools as a means of supporting that interaction.

Less literate people interpret graphics literally. Accompanying text, only partially understood, provides clues to the content of pictures, not the reverse. Details of the representation, including the use of colours, influence how they are understood. For instance, for study participants yellow or gold symbolises wealth and red symbolises death. For them, posters that use these colours confirm that people are making money out of the ‘Ebola business’. Images that do not reflect the cultural context, such as pictures of women in short skirts or performing burials, create confusion and concern. Focus group participants, regardless of age or gender, value pictorial communication. They called for accompanying text to be in Nande and Lingala as well as French and localised Swahili. They also want numbered pictures to make the sequencing clear, and leaflets they can take home for reference.

In the absence of individual reference materials, posters are an important communication tool, supporting but not replacing verbal explanation. However, many posters in Beni were either hard to read as a result of weather damage, or kept in health facilities where few could see them. Participants called for posters to be laminated to last longer outdoors.

Audiovisual materials from the response archive were popular with focus group participants, but are rarely made available. Film documentaries showing real people and places lend credibility to explanations of processes such as treatment, vaccination and burial. The video we showed a group of young people sparked animated discussion, which could be a basis for addressing rumours and misunderstandings. If communication teams had the equipment to project documentaries, the response could make better use of this resource.

Responding organisations can take practical steps to improve communication on Ebola

The study suggests ways to improve community engagement in both the current and in future disease outbreak responses. In particular, responding organisations should:

- Provide information in local languages, including localised variants of languages such as Swahili and Nande.
- Provide regular training to health communicators in their language on all aspects of the response, and update training materials as policies and practices change.
- Support health communicators to translate key concepts into accessible and accurate explanations in local languages, and develop tools and training that draw on their cultural expertise.
- Use more accessible and patient-centred language,

and avoid technical terminology, foreign loanwords and warlike vocabulary.

- Explain the reasons behind policy and practice changes, and provide health communicators with regularly updated plain-language answers to people's questions.
- Develop detailed, updated graphic and audiovisual materials and test them for comprehension and social acceptability.

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What do adaptations tell us about the production of trust? Shifting the 'burden of change' from people to the response

Sung-Joon Park, Nene Morisho, Kennedy Wema Muhindo, Julienne Anoko, Nina Gobat, Hannah Brown and Matthias Borchert

This article, based on our research project on 'Humanizing the design of the Ebola response in Eastern DRC', examines the role of adaptation in the production of trust. The project has been chiefly concerned with exploring how humanely designed care and treatment for Ebola contribute to the formation of trust. In past epidemics, the need to provide safe care and treatment of Ebola patients posed enormous ethical challenges for health workers and relatives wishing to provide the best care possible.¹ In the West Africa Ebola epidemic, practitioners, patients and observers alike were at times appalled by the conditions under which patients were isolated in Ebola Treatment Centres (ETCs).

Since the epidemic in the DRC began in 2018, more than 3,400 cases have been recorded, and 2,240 people have died, making this the second-largest Ebola epidemic in history. One crucial lesson from past epidemics, and one that was applied in the current Ebola response in Eastern DRC, is the use of novel treatment facilities called CUBE (Biosecurity Emergency Care Units), developed by the medical relief organisation ALIMA. These facilities consist of chambers with transparent plastic walls, which allow medical staff to provide more individualised care. Relatives can easily visit their loved ones and observe them through the transparent walls, and doctors can perform life-saving interventions quickly without

the need to wear full personal protective equipment (PPE). Together with new therapies trialled during the epidemic, these innovations dramatically reduced case fatality and improved the acceptability of the response.

These innovations in the clinical care of patients have been introduced in an environment of mistrust between emergency responders and communities. This mistrust cannot be easily repaired without addressing the larger political, historical and social context of the epidemic.² Terms such as mistrust and resistance point to a broad range of interlinked issues, including weak health systems, neglect and insecurity, and influence how emergency response teams and communities relate to each other in Eastern DRC.³

Early humanistic conceptions of care for Ebola and the social study of adaptation

Anthropologists have long underlined the importance of 'humanistic', culturally relevant conceptions of care and the need to develop 'alternative culturally sensitive' strategies for the isolation of patients to enhance community acceptance of the emergency response.⁴ New treatment facilities like

1 Christopher J.M. Whitty et al, 'Tough Choices to Reduce Ebola Transmission', *Nature*, 515, 2014; Paul Richards, *Ebola: How a People's Science Helped End an Epidemic* (London: Zed Books, 2016); S.J. Park and G. Akello, 'The Oughtness of Care: Fear, Stress, and Caregiving During the 2000–2001 Ebola Outbreak in Gulu, Uganda', *Social Science & Medicine*, 194, 2017 (<https://doi.org/10.1016/j.socscimed.2017.10.010>. www.ncbi.nlm.nih.gov/pubmed/29073506).

2 James Fairhead, 'Understanding Social Resistance to the Ebola Response in the Forest Region of the Republic of Guinea: An Anthropological Perspective', *African Studies Review*, 59(3), 2016.

3 Vinh-Kim Nguyen, 'An Epidemic of Suspicion: Ebola and Violence in the DRC', *New England Journal of Medicine*, 318, 2019; Eugene T. Richardson, Timothy McGinnis and Raphael Frankfurter, 'Ebola and the Narrative of Mistrust', *BMJ Global Health*, 4, 2019.



The isolation unit of the temporary transit center (Centre de Transit Temporaire) created at Health Center Mdrandele/Beni.

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the CUBEs are in many ways a realisation of this humanistic conception. They underscore the importance of proximity, for example by allowing relatives to visit their loved ones, and show that these innovations contribute to improved clinical care.⁵ In addition to the development of culturally sensitive strategies, the research has been concerned with extending our analysis to the study of materials, technologies and infrastructures that make alternative forms of care possible.⁶ Paying attention to these material and technical objects allows us to study how actors and organisations adapt their responses to specific contexts and problems.⁷

Humane designs of care and treatment are a case in point for exploring adaptation as a social activity. When we began our research in August 2019, our interlocutors were deeply concerned with understanding how the emergency response had gone awry, for example by the expensive recruitment of non-local staff, which had angered local communities. Like other researchers, the project has been looking more carefully at the sources of this mistrust. In November 2019 we began to ask how the designs of ETUs were adapted to build trust and thereby repair the relationship between the response and communities. Our interlocutors spoke with great confidence about the various changes they had been initiating to 'adapt to the communities'. Such insights are fundamental

to developing creative and (partly) unplanned measures to improve the relationship between responders and communities, and show how standardised blueprints can be adapted to concrete and unique circumstances.⁸

Adaptations of humane care beyond ETCs

An exemplary case of adaptation was the decentralisation of care initiated by Médecins Sans Frontières (MSF) and ALIMA from March 2019 onwards. In Beni, one of the hotspots of the epidemic, MSF France started devolving testing and the isolation of suspected cases to public health centres. Beforehand, Beni had had one transit centre (for suspected patients) and one Ebola treatment centre (for confirmed cases). The new structures, called temporary transit centres (*centres de transit temporaires*), aimed at bringing Ebola-related health services closer to communities. An important component of this initiative was to support these transit centres in the provision of free care for all health conditions, to counter the tendency to reduce healthcare simply to Ebola, which had angered communities who felt that their wider health needs had for many years been neglected.

The temporary transit centres have an isolation unit in the compound comprising two or three chambers where patients are isolated until results arrive. If the tests are positive, they are taken to the ETC. The chambers resemble the isolation units in the main ETCs. Each room has a bed, a chair and a toilet. Relatives visiting their loved ones stand at a railing outside the isolation rooms. This decentralisation was not necessarily planned: as the MSF coordinator for Nord Kivu told us, it was initiated as a response to attacks on ETCs in Katwa in

4 Barry Hewlett et al., 'Medical Anthropology and Ebola in Congo: Cultural Models and Humanistic Care', *Bulletin de la Société de pathologie exotique*, 98, 2005.

5 Hannah Brown and Almudena Marí Sáez, 'Ebola Separations: Trust and Crisis in West Africa', *Journal of the Royal Anthropological Institute*, forthcoming.

6 Hannah Brown et al., 'Extending the Social: Anthropological Contributions to the Study of Viral Haemorrhagic Fevers', *PLoS Negl Trop Dis*, 9(4), 2015; Stacy Leigh Pigg, 'Found in Most Traditional Societies: Traditional Medical Practitioners between Culture and Development' (Berkeley, CA: University of California Press, 1997).

7 Pigg, 'Found in Most Traditional Societies'.

8 Andrea Behrends, Sung-Joon Park and Richard Rottenburg, *Travelling Models: Introducing an Analytical Concept to Globalisation Studies* (Leiden: Brill, 2014).

February 2019, which marked the beginning of a second wave of transmission.

Initially, other response organisations were reluctant to follow MSF's approach, though after a few weeks most had adopted the model under the label 'decentralised transit centre'. Staff working at the health centres we studied often stressed that, while support came international organisations, local communities had started to take ownership of the transit centres. According to health workers at the centres, attendance rates had increased significantly. As one explained:

it's a good initiative because the population feels responsible for the structure. They want the health centre to reach even 1,000 consultations and that all of the women come here to give birth. The population has appropriated the centre and complain if a staff member hasn't done his job properly.

A range of adaptations was also introduced to the existing infrastructure of the Ebola response. In particular, staff at the main transit centre in Beni emphasised how many changes had been made. They had set up a restaurant and a tent to provide privacy for counselling relatives of patients, and installed a latrine in the waiting area. These improvements may sound like basic changes, but as one doctor explained, if 'you ask people to be there from 8am to 2pm ... during that time you may need to pee'. Yet, as he went on to explain, 'Imagine, in this [transit centre], we have been asking for three months to build a latrine here at the reception desk'. He recalled how even having a debate about this at all was seen to be 'too demanding': 'why in Congo do you need something of such high standard?'. He countered such complaints by saying 'being Congolese doesn't mean you have to suffer'; he was convinced that changes to improve care for Ebola patients should not be too onerous, and are often not even expensive.

The meaning of 'humanising' patient care

Looking at adaptations to improve care and treatment beyond ETCs provides crucial insights into the production of trust. It shows how new treatment facilities can be adapted to

reorganise modalities of care within public health systems, thereby giving rise to new approaches. As they are embedded in social interactions and infrastructures, adaptations can occur unexpectedly, arising out of the lived experiences of health workers, through negotiations between different actors and a recognition that care for patients has to improve.

Our research shows that adaptations to humanise care are not always readily accepted by decision-makers. Reluctance to implement innovations may stem from considerations of biosafety requirements or cost concerns. Yet, the creation of temporary transit centres highlights the crucial point that communities participate in determining what adaptations are worth copying because they are perceived as useful in improving health and safety. Such adaptations in turn have a greater chance of being 'owned' by communities.⁹

Ignoring modes of cooperation based on mutual respect risks enforcing boundaries between different actors in the response, notably between local and non-local staff or the response and the community, fuelling a distinction between 'us' and 'them', which reproduces mistrust. This mistrust is a social consequence of the architecture of the response. Adaptation, by contrast, demonstrates how crucial it is to shift the burden of change from people to the response.

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9 Joao Biehl, 'Theorizing Global Health', *Medicine Anthropology Theory*, 3(2), 2016; Richards, *Ebola*.

Community engagement: the key to successful Ebola research

Stephen Mugamba, Jauhara Nanyondo, Monica Millard, Naoko Kozuki and Hannah Kibuuka

Community engagement is a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being. Ideally, it should draw on locally contextualised meanings derived from experiences and lessons learnt during the implementation of community engagement activities. These activities include information-sharing with stakeholders and getting feedback, deliberate steps to close feedback loops, small doable actions to resolve

community challenges and encourage meaningful dialogue that aim at reaching a consensus between communities and those engaging with them.

Community engagement is rooted in the demands of community leaders, policy-makers and funders for meaningful community involvement to address health problems. As such, it is a key pillar of research. It increases a community's

understanding of issues under study, and enhances the ability of researchers to understand community priorities, the importance of addressing community priorities and the need for culturally sensitive approaches to communications and research.¹

Interventions can have a positive impact on a wide range of health outcomes, but there is insufficient evidence to identify whether one particular model of engagement is more effective than another.² It is also difficult to disentangle the contribution of community engagement from the other strategies usually employed to ensure successful interventions.³ This is probably one of the reasons why, conventionally, organisations and institutions implementing activities or conducting research in Uganda have often not adequately taken community engagement into consideration, or allocated a very small budget to it. Only very recently have global funding bodies such as the Wellcome Trust and the Bill and Melinda Gates Foundation begun to promote and offer specific funding for community engagement, in addition to research and programme funding.

In the past decade, Uganda has seen the professionalisation of community engagement in the conduct of biomedical research, based largely on the concept of Good Participatory Practice (GPP) for Biomedical Research, developed by the Global Advocacy for HIV Prevention (AVAC) and the Joint United Nations Programme for HIV/AIDS (UNAIDS).⁴ Prior to the launch of the guidelines in 2011, there was limited documentation of how community engagement for biomedical HIV prevention research should be conducted. The guidelines provide advice and a formalised framework for funders and researchers on how to engage communities in the design and conduct of biomedical research. Like the Good Clinical Practice (GCP) principles, GPP is based on the principles of beneficence, respect, accountability and transparency. In July 2014, the Uganda National Council of Science and Technology (UNCST) launched and incorporated GPP principles in the National Guidelines for Research Involving Humans as Research Participants, and since then the guidelines have been adopted by research institutions in Uganda. Given the initial focus on HIV prevention research, the guidelines cannot be adapted wholesale to non-HIV clinical trials, though AVAC and other partners have modified them for trials of emerging (and

re-emerging) pathogens likely to cause severe outbreaks, and for which few or no medical counter-measures exist.⁵

Regardless of the absence of uniform guidelines, community engagement and their strategic involvement have often emerged as important and necessary for supporting the involvement and retention of research participants in studies. Makerere University Walter Reed Project (MUWRP), a research organisation, has engaged communities and other key stakeholders for community education, recruitment and retention in various clinical studies, including Ebola vaccine studies in Kampala, and has also been part of government efforts in south-west Uganda to build supportive structures for Ebola preparedness and response at Fort Portal Regional Referral Hospital.

MUWRP has been at the forefront of Ebola vaccine research since 2009, when it conducted the first Ebola and Marburg vaccine trial in Africa.⁶ Given that the local population was unaware of Ebola clinical research, MUWRP used a multi-channel approach to keep communities informed. MUWRP has used the same approach for subsequent Ebola vaccine trials, including stakeholder meetings, high-level dialogue with parliamentarians, participation in local events such as National Health Days, ongoing dialogue with community-based organisations, town hall meetings, radio and television talk shows, NGO forums and engagement with the MUWRP Community Advisory Board (CAB).

Box 1: About the Community Advisory Board (CAB)

Research institutions in Uganda are required to constitute a CAB to link the researchers and the community where research is being conducted. CABs are best described as the ‘mouthpieces of the community and the eyes of the researcher’. Members typically include community leaders, representatives of women and youth, religious leaders, health workers, media practitioners, civil society representatives, affected people and, occasionally, artists.

MUWRP’s CAB has 13 members. It convenes a quarterly meeting, but can meet ad hoc to address unanticipated problems or recruitment challenges. The team supports reviews of study-related documents to ensure that research is socio-culturally acceptable, and there is mutual understanding between researchers and the community. The CAB also helps translate the complex scientific language of research protocols into easy concepts, facilitating informed decision-making.

1 Syed M. Ahmed and Ann-Gel S. Palermo, ‘Community Engagement in Research: Frameworks for Education and Peer Review’, *American Journal of Public Health*, 100(8), August 2010).

2 E. De Weger et al., ‘Achieving Successful Community Engagement: A Rapid Realist Review’, *BMC Health Services Research*, April 2018.

3 Alison O’Mara-Eves et al., ‘The Effectiveness of Community Engagement in Public Health Interventions for Disadvantaged Groups: A Meta-analysis’, *BMC Public Health*, February, 2015.

4 Natasha Mack et al., ‘Implementing Good Participatory Practice Guidelines in the FEM-PrEP Preexposure Prophylaxis Trial for HIV Prevention among African Women: A Focus on Local Stakeholder Involvement’, *Open Access Journal of Clinical Trials*, October 2013.

5 Catherine Hankins, *Outcome Document of the Consultative Process*, World Health Organization, Dakar, December 2016.

6 Hannah Kibuuka et al., ‘DNA Vaccines Assessed Separately and Concomitantly in Healthy Ugandan Adults: A Phase 1b, Randomised, Double-blind, Placebo-controlled Clinical Trial’, *The Lancet*, December 2014.

Case study 1: The stakeholders' consultative meeting on Ebola vaccine research

Before MUWRP conducted the first Ebola clinical trial in 2009, a community-wide stakeholder meeting was held to build community support for the research. Community members were dubious about participating in a trial at a time when the country did not have Ebola, and the trial's target population in Kampala had not previously experienced an Ebola outbreak. Community members did not regard Ebola as a major issue that required a vaccine, and wanted the researchers to focus on looking for an HIV vaccine.

The following stakeholders were invited to a series of meetings: Ministry of Health line departments, the National Drug Authority, ethical regulatory bodies, political leaders, Kampala-area public health officials, security officials, religious leaders, the media,

representatives of community members and members of the MUWRP CAB. Key concepts were discussed, including the importance of clinical trials to test vaccine safety and immune responses, even at a time when there was no outbreak. Community stakeholders advised on the most appropriate channels and messaging during the study.

The outcome of these meetings was an engagement strategy that sought to allay the concerns of the target community. In addition, the engagement garnered political support and mobilised policy-makers and other key stakeholders to support the conduct of the clinical trial. Media houses that attended the meeting subsequently provided airtime and space to address community concerns regarding why the vaccine trial was needed.



8 January 2019 – Beni, North Kivu region, Democratic Republic of Congo. Community representatives come to visit a family in the outskirts of Beni to raise awareness about Ebola.

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MUWRP has used the lessons from community engagement activities in other Ebola vaccine trials, recruiting from a range of population groups including adolescents and children. According to Jauhara Nanyondo, MUWRP's Community Outreach Coordinator, in her 12 years' experience 'We had never conducted clinical trials that enrolled children. Consent not only involved the research participant alone, but also the parents/guardians, which made the recruitment process longer and more complex'. The solution to this challenge was to enroll older participants (18+) first, inform them of the intention to recruit children aged between six and 17 and seek their permission to enroll their own children.

Whereas community engagement is central to public health research and interventions, it is even more important to ensure the buy-in and meaningful participation of communities during an actual public health emergency. Lessons from Ebola outbreaks in North Kivu in the Democratic Republic of Congo (DRC) and in West Africa underscore the crucial role of community engagement in ensuring better outcomes for Ebola research, preparedness and response activities. For example, strong community resistance and low levels of trust towards the Ebola response severely hindered the implementation of Infection Prevention Control (IPC) programmes. In some instances, this resulted in attacks on response workers and health facilities. Community engagement in such settings puts communities at the heart of the response by building transparent, meaningful, collaborative and mutually beneficial relationships with interested or affected individuals, groups, organisations and government bodies, with the ultimate goal of achieving acceptable health standards.

The importance of incorporating community engagement in Ebola programming and research, especially during outbreak response, is becoming more and more apparent. The challenges and lessons from the DRC and West Africa have helped to highlight gaps that current and future programming on Ebola will address. For example, there is a need to address issues around inadequate communication with communities, misconceptions around the disease, limited knowledge of local culture and customs among response actors and a lack of involvement of local communities in control strategies, including handling suspected cases and safe burial.

Recently, MUWRP has partnered with the International Rescue Committee (IRC) to conduct a study to evaluate a newly designed community engagement model that seeks to place power in the hands of key community members to develop

and execute action plans to increase awareness and uptake of Ebola prevention behaviours, as part of IRC's Ebola preparedness activities in Kasese District in Uganda. The model, which we called 'Active Listening Sessions', embraced two key principles: ensuring strong feedback loops that support two-way dialogue between the community and responders; and ensuring community ownership of Ebola prevention and response. Participants were selected based on their risk of exposure to Ebola, social influence and willingness to engage, and had an identifiable community member (ambassador or champion) to support the work. For the study, we engaged women's groups, village health teams and community health workers. Over the course of four meetings spread out over 1–2-week increments, groups developed action plans to disseminate key messages in their communities. We are in the process of synthesising the results to determine how involving community engagement activity in a systematic way can improve trust in and compliance with prevention measures during Ebola preparedness and response.

MUWRP's community engagement work has contributed to a deeper understanding of communities' culture, perceptions, social networks, political and power structures, norms and values. It has also helped the Community Outreach team to define demographic trends and record past experiences of Ebola and other hemorrhagic fevers, and enabled formal and informal community leaders to support public health research.

Our experience demonstrates that community engagement is critical in establishing and maintaining community involvement in Ebola research. We have learned that this is a complex process that calls for perseverance, commitment, expertise and dedicated resources. We are yet to establish how relevant and practical our engagement model could be in terms of risk communication and social mobilisation during emergencies, but the lessons learned from supporting Ebola research have greatly improved our understanding of community perceptions of the disease, and can inform the development of innovative community engagement in emergencies.

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Sexual and reproductive health in Ebola response: a neglected priority

Gillian McKay, Benjamin Black, Alice Janvrin and Erin Wheeler

As of March 2020, the Ebola outbreak in North Kivu and Ituri in the Democratic Republic of Congo (DRC) had claimed more than 2,200 lives. Women and girls make up 56% of the almost 3,500 confirmed cases. Stopping transmission of the virus has been the primary focus for the Ministry of Health and responding agencies, often to the detriment of other critical health services, including sexual and reproductive health (SRH).

Women, girls, men and boys continue to have SRH needs during conflicts and epidemics. Physiologically, women and girls bleed: due to menstruation, the side-effects of family planning and during abortions or obstetric emergencies. The case definition for Ebola includes 'spontaneous abortion' and 'unexplained bleeding' as criteria for isolation and testing. There is also significant overlap between the vague presenting symptoms of Ebola and pregnancy complications. The broad application of the case definition can therefore result in women and girls being prevented or delayed from getting appropriate (sometimes life-saving) care for non-Ebola health conditions, out of an overabundance of caution.

Assessment of the impact of Ebola on SRH in DRC

Between October and December 2019, the IRC conducted a programme assessment to document how the current DRC outbreak has impacted SRH access and provision, in order to develop concrete recommendations for this and future outbreaks. The assessment, which took place in five Ebola-affected health zones in North Kivu, involved group discussions and individual interviews with 120 people. Three routine health facilities were also evaluated for their SRH and Ebola readiness, and the team visited one Ebola Treatment Centre (ETC).

The assessment was structured around the Interagency Working Group for Reproductive Health in Crises' Minimum Initial Service Package (MISP), a package of life-saving services implemented at the start of a humanitarian crisis to minimise negative SRH consequences, including maternal mortality and morbidity. Overall, it found that most SRH services were negatively affected by the outbreak. However, the negative effects of the outbreak on SRH have been mitigated over time in the 18 months since the start of the outbreak, with increased community sensitisation, testimonials from Ebola survivors about their treatment experience and deliberate hiring of Ebola response workers from local areas.

Activity 1: Identification of an agency to lead the implementation of the MISP

Under the pre-existing humanitarian response in conflict-affected North Kivu, UNFPA was the designated lead SRH agency. However, Ebola coordination takes place parallel to the health cluster, with little interaction between the two, resulting in SRH being neglected in the face of the Ebola response. As one respondent put it: 'We have the small voice of SRH, it's hard to make your voice heard with all of the millions of [Ebola] money'. SRH-focused organisations may also fail to adapt their approach during Ebola, as they can suffer the same tunnel vision where they only see pre-existing SRH needs, without considering the added complexities created by the parallel coordination structure.

Activity 2: Prevent and manage the consequences of sexual violence

Protracted conflict drives pervasive sexual violence in North Kivu. Access to care for survivors of sexual violence has been affected, with healthcare workers describing survivors avoiding or delaying care.

We had a case of sexual violence that was impeded from coming here to the hospital. There was a case of two children who had been raped, and one was bleeding. The child had been at home one week at least while she was bleeding. The family got information that they should come into hospital. So the family came here to the hospital, the mother, father and two children, we looked them all over and talked to the parents and the children and they told us what happened. They told us that because of the situation of this time [Ebola] they were afraid to come to the hospital because the child was bleeding and they did not have the courage to go to the hospital as she could be taken away to the Ebola Treatment Centre. It was more than 72 hours [after the rape] so we couldn't do much to help the child.

Activity 3: Reduce transmission, mortality and morbidity from HIV and other STIs

The outbreak does not seem to have affected testing and treatment for HIV in routine (non-Ebola) healthcare facilities. However, such services were lacking in ETCs, with one informant admitting that HIV care had not been considered in their organisation's ETC. STI testing and treatment appear to have benefited from the outbreak, with significant increases likely linked to Ebola-related free healthcare initiatives.



Ebola temperature screening at a health facility in North Kivu, August 2018.

© K. Ryan, IRC

Scientific knowledge about the sexual transmission of Ebola continues to be debated. This has resulted in contradictory messages from response actors to communities, and confusion about how long Ebola survivors are thought to be able to transmit, with community members stating that Ebola could be transmitted sexually from 250 days to two years.¹ In a context where condom use is historically low, several respondents believed that the use of condoms was of increased importance during the Ebola outbreak: 'More people are using condoms now in this Ebola time, because people are afraid of Ebola so they want to prevent'.

Activity 4: Prevent excess maternal and newborn morbidity and mortality

The Ebola outbreak has significantly affected women's ability to seek timely care for pregnancy complications, with consequent impacts on the woman and the foetus. Maternal mortality is often attributed to delays in deciding to seek, gain access to and receive appropriate healthcare. This is known as the 'Three Delays Model', though the assessment found that the outbreak had added further delays:

- **Delay 1:** The fear of being sent away to the ETC for testing, or fear of catching Ebola at the health facility, deters women from seeking care for routine and emergency healthcare needs. 'They come late because they are afraid of the Ebola so that's why they delay.'

There is a woman who delivered at the hospital, after she delivered they changed the bed and moved her into another bed. After she left the hospital, after one week she presented with Ebola. After two weeks she died and left her baby. When they moved the lady, they moved her onto a bed that was previously someone with Ebola and that's how she got sick. It's after this event that women became afraid to come and go and deliver in the hospital and they would prefer to go to the private health centre, the places where there was no triage. We are afraid because if we have a fever even if it's due to something normal like malaria or high blood pressure then we can be sent to the ETC.

- **Delay 2:** It can take additional time to travel to a healthcare facility due to Ebola screening posts along major roads. Women may initially choose to go to a traditional healer, or to a pharmacy to seek medicine, out of fear of being sent to the ETC. Health facilities may also close temporarily during periods of heightened insecurity, further hampering women's access to appropriate care: 'She was very afraid to give birth because when she came to the health clinic they had closed for a week [due to healthcare workers having to flee violence], so she had to travel to the [large hospital] to deliver ... by the time she got there after walking for a long time she delivered her baby within an hour'.
- **Delay 3:** On arriving at a health facility, women are triaged for signs or symptoms of Ebola, and if they

¹ Note: the length of time Ebola survivors can transmit could be up to 18 months, but the evidence is still in flux: see www.mdpi.com/1999-4915/10/12/683/htm.

meet the case definition they will be isolated (for the safety of staff and other patients), while waiting to be transferred to the ETC for testing. The broad crossover of pregnancy symptoms and the Ebola case definition, and the fact that some healthcare workers are not confident triaging, means that many pregnant women with complications are isolated. While in isolation, they may or may not be provided with an appropriate level of care for their health condition.

We had a woman with a full term who came during the night, at 9pm bleeding with contractions. We diagnosed placental abruption as soon as she arrived as she had the signs. The triage team blocked her in isolation. They did a local blood draw and she waited [for results] all night. Her blood pressure crashed, she needed surgery. In full PPE, we did a hysterectomy. The fetus was already dead, but she was saved. Her results came back in the evening and she was negative. The mother would not have undergone a hysterectomy if there hadn't been the triage we would have only evacuated the uterus and leave it there.

- **Delay 4:** If a woman needs to be transferred to the ETC for testing, the ambulance can take up to an hour to reach her, with further delays while she travels to the ETC. In some facilities it is possible to do a local blood test to check for Ebola, but the results may take several hours.
- **Delay 5:** Women experiencing pregnancy complications who are transferred to an ETC still require obstetric care, and many will not be Ebola-positive.² Final test results can take from six to 48 hours from admission, resulting in cases where women who test negative are still in the ETC when they go into labour. Decisions around offering obstetric interventions varied between ETCs. Deciding to take a suspected or confirmed Ebola patient for an invasive procedure (like a cesarean section) is complex where the safety of healthcare workers must be carefully considered.

Activity 5: Prevention of unintended pregnancy

Many women and men stated that 'Ebola time is a good time to plan your family. The women can take the [contraceptive] methods now and have another baby after the outbreak'. A number of women (including healthcare workers) reported using various pregnancy prevention methods for fear of being sent to the ETC should they have pregnancy complications. Unfortunately, the full range of modern contraceptives was not provided in ETCs (for patients or healthcare workers) and were rarely available at primary health care facilities.

² In an ETC dataset with admissions up until October 2019, of the 426 pregnant women who were referred for Ebola virus testing (EVD): 15% had EVD, the rest had a non-EVD cause for their symptoms.

Activity 6: Plan for comprehensive SRH integrated in primary healthcare services

Although access to SRH services has improved, key gaps remain in the access to and quality of comprehensive SRH services at the primary care level. Healthcare workers reported that the Ebola outbreak had improved some aspects of care at their facilities, mainly related to infection prevention and control (IPC), and they are eager that these improvements should be maintained post-outbreak.

Other priority activity: safe abortion care should be made available to the full extent of the law

The DRC ratified the Maputo protocol in 2018, making access to safe abortion care legal in some circumstances. It was not clear if the Ebola outbreak had increased or decreased the number of women inducing an unsafe abortion, though as one healthcare worker noted: 'Since the start of the epidemic all bleeding is a suspect [Ebola case]. Even when it's an abortion, even if you induced your own abortion, it's a suspect [Ebola case]'. The assessment found that some ETCs have appropriate medication and equipment to provide safe abortion care, but it was not clear if protocols for this existed and safe abortion care was largely unavailable at primary health care facilities and ETCs.

Recommendations

These recommendations were developed to improve SRH care during the current DRC outbreak, but should also be considered in preparedness efforts for future outbreaks of Ebola and other viral hemorrhagic fevers.

1. SRH services should be embedded in Ebola response from the outset, ensuring the mainstreaming of SRH within the response, together with Ebola-sensitive SRH services. The MISPP should be activated, with the transition to comprehensive SRH services as soon as possible.
2. Reduce delays at every stage of the patient journey, particularly for women experiencing obstetric complications. Work with the Ebola response coordination structure to ensure that triage processes and care for pregnant women in ETCs reduce unnecessary delays in receiving appropriate care, while maintaining a universal level of IPC. Rapid Ebola testing and novel Ebola prevention and care technologies should be offered to pregnant women where possible. Positive messaging about improved survival for early care-seeking (for pregnancy complications and Ebola) and policies to facilitate this behaviour (i.e. free healthcare) should be implemented.
3. Mitigate SRH risks during and after Ebola outbreaks by providing modern family planning methods and comprehensive abortion care at routine health services and in ETCs for those who choose to delay or terminate pregnancy. Uninterrupted HIV care should be provided at ETCs. Condom use should be promoted to reduce

STIs and sexual Ebola transmission for Ebola survivors and the general population, particularly for people who sell sex or who are at risk of commercial sexual exploitation. Messages about sexual transmission of Ebola should be harmonised and non-stigmatising.

4. Evidence-based guidelines for SRH care in an Ebola context must be developed by experts from relevant fields, and must include the delivery of services in ETCs, in routine health facilities and in communities. These guidelines must be made available to frontline staff (in a variety of languages) and regularly updated with new evidence.

Conclusion

Outbreaks of viral hemorrhagic fevers are unlikely to become less frequent in future. Uptake of recommendations from

assessments like this one are imperative to ensure we do not continue to make the same mistakes, neglecting critical aspects of routine healthcare when the efforts and energy of the humanitarian health community are focused on stopping transmission of a novel pathogen. Meeting the SRH needs of communities, especially women and girls, during an outbreak is crucial to prevent excess morbidity and mortality.

Gillian McKay is a global health consultant. **Benjamin Black** is an obstetric and gynaecology humanitarian advisor. **Alice Janvrin** and **Erin Wheeler** are with the International Rescue Committee. To read the (much more comprehensive) programme assessment, go to www.rescue.org/report/not-all-bleeds-ebola-how-drc-outbreak-impacts-reproductive-health.

NGO readiness for Ebola: a practical roadmap

Stacey Mearns, Kiryn Lanning and Michelle Gayer

The Ebola outbreak in eastern Democratic Republic of Congo (DRC), declared on 1 August 2018, is the second-largest in history. The DRC shares its borders with nine countries, all of which are at high risk for an Ebola outbreak given the regular cross-border movement of people, goods and services in the region. NGOs are increasingly playing a critical role in Ebola responses, complementing and contributing to the efforts of national governments and UN agencies. Yet there is little guidance to support NGO preparedness for Ebola.

Ebola outbreaks can challenge NGOs' capabilities in many ways; effectively preparing for Ebola within an NGO is a complex undertaking involving many departments across all levels of the organisation. The existing World Health Organization (WHO) Ebola preparedness checklist is intended for use by national governments preparing for Ebola, and as such does not fully consider the cross-departmental and multi-dimensional actions required within NGOs. Furthermore, existing NGO general emergency preparedness plans and approaches, which typically take an all-hazards approach, do not fully align with the preparedness required for a specific and imminent risk such as Ebola.

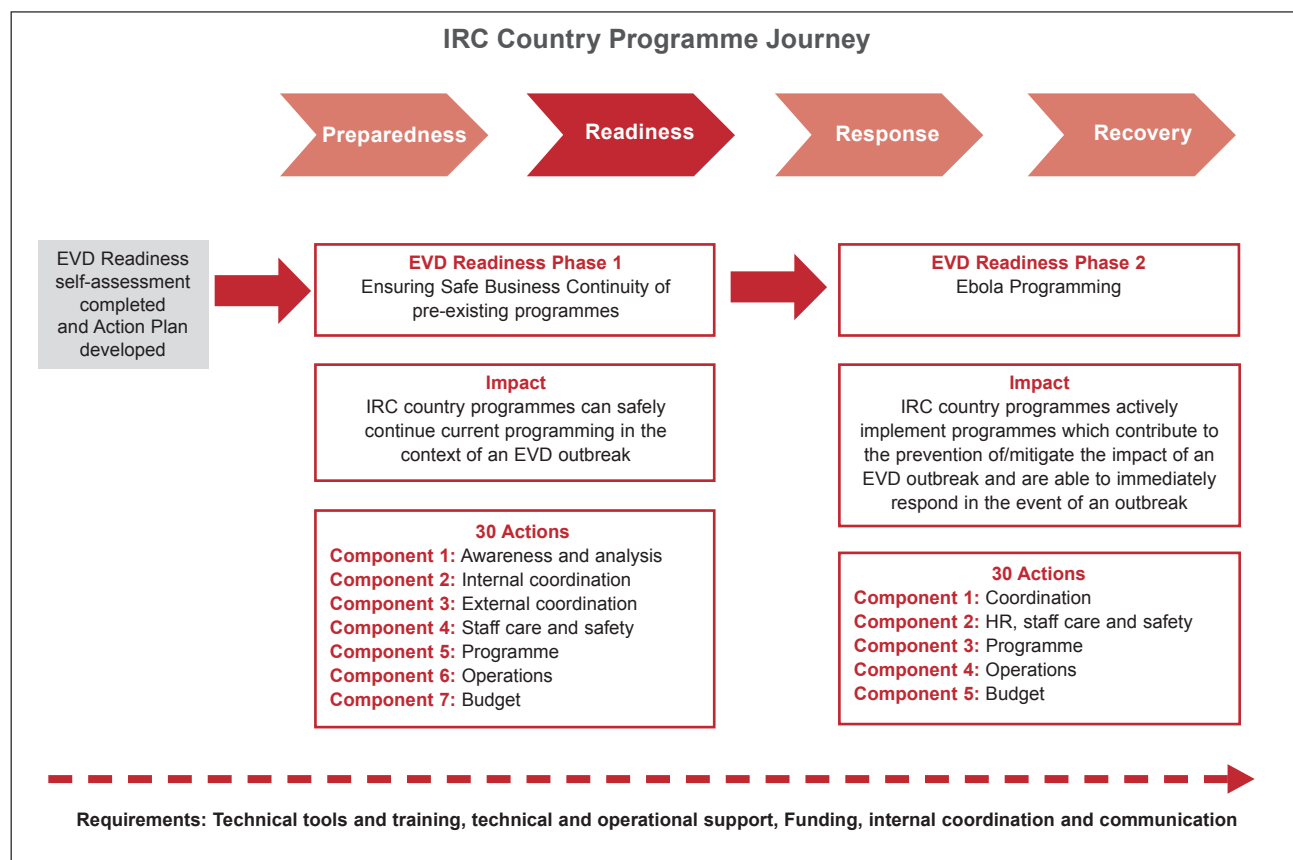
The International Rescue Committee (IRC) currently has country offices and pre-existing programming in five of the nine high-risk countries. To assist Country Programmes operating within these countries, the IRC developed an Ebola Readiness Roadmap to support Ebola preparedness actions. This article looks at the IRC's approach to Ebola readiness in these high-risk countries, and presents the Roadmap as one way to support operational practice for NGOs preparing for an outbreak.

IRC's Ebola preparedness journey

The IRC's approach to Ebola preparedness has evolved over the course of the outbreak in eastern DRC. At the beginning, there was no clear vision or expectations for IRC Country Programmes in neighbouring at-risk countries, and no specific Ebola preparedness tools to support them. The initial approach to Ebola preparedness involved meetings with Country Programme managers to discuss broad actions and general guidance on staff awareness and safety, and where IRC had any health programming in that country, guidance was provided on strengthening surveillance and Infection Prevention and Control (IPC), using WHO online resources. However, Country Programmes had multiple ongoing projects in a variety of sectors, and found it difficult to define, choose, sequence and operationalise actions. Around 10 months into the outbreak, and following requests from Country Programmes for practical tools outlining specific and concrete actions to take in preparing for Ebola, the IRC developed an Ebola preparedness checklist. The initial checklist was based on operational experience the IRC had gained responding to Ebola in Sierra Leone and Liberia during the outbreak in 2014–2016, in DRC in 2018 and in the ongoing North Kivu/Ituri outbreak. It consisted of components and actions designed to enable Country Programmes to rapidly scale and safely deliver Ebola programming.

After being rolled out in IRC at-risk countries, the checklist was updated to reflect feedback and learning, in particular how to safely maintain pre-existing programmes while also preparing to respond specifically to Ebola, and most importantly, the need to prioritise actions within the checklist, taking into consideration the variety of projects and the many competing priorities faced by Country Programmes, and the need for simpler tools, resources and concrete examples to support implementation.

Figure 1: The IRC Ebola Readiness Roadmap



Requirements: Technical tools and training, technical and operational support, Funding, internal coordination and communication

Source: This was developed by IRC, the authors of this article.

The revision of the checklist resulted in the development of the IRC Ebola Readiness Roadmap. As part of this revision, a distinction was made in terminology between Ebola *preparedness* and *readiness*, terms often used interchangeably. The IRC currently has programmes in 12 countries at risk of Ebola outbreaks; as such, we wanted to separate Country Programmes where Ebola is a potential hazard from those where it is an actual hazard. This would enable the IRC to be more proportionate in the support provided to Country Programmes relative to risk. We have chosen to define Ebola readiness as the actions taken by at-risk countries in response to a confirmed Ebola outbreak (imminent risk). This is achieved through the implementation of the IRC Ebola Readiness Roadmap, and takes place in IRC Country Programmes neighbouring an active Ebola outbreak.

IRC Ebola Readiness Roadmap

The Roadmap is designed to facilitate effective implementation of Ebola readiness actions by IRC Country Programmes. It can be used by Country Programmes to assess their level of readiness, and identify key gaps. Spanning the systematic, structural and functional domains required for effective readiness, the Roadmap is split into two distinct phases, each with a corresponding set of actions (Figure 1).

Phase 1 of the Roadmap, which centres on ensuring business continuity, includes 30 actions across seven components. At

Figure 2: Staff safety dimensions



Source: IRC

the end of this phase, IRC Country Programmes should be able to safely continue their current programming in the context of an Ebola outbreak. Priority is placed on ensuring the continuity of pre-existing programmes, recognising the broader impacts of Ebola outbreaks. Example actions within phase 1 include

linking to existing external Ebola coordination mechanisms, and the establishment of internal coordination systems. A programme risk assessment is completed for the whole Country Programme portfolio to identify mitigation measures to be implemented to minimise risks associated with current programming in the event of an Ebola outbreak. From the operations side, actions in this phase centre on optimising existing support functions. The major emphasis during this phase is on staff safety, ensuring that IRC staff have the knowledge and supplies they need to work safely, and that the organisation has the right policies and safeguards in place to support staff and mitigate risk. Staff safety consists of different dimensions (Figure 2), each with corresponding actions.

Phase 2 of the Roadmap centres on Ebola-related programming, and includes 33 actions across five components. At the end of this phase, IRC Country Programmes are actively implementing programmes which contribute to the prevention of, or mitigate the impact of, an Ebola outbreak, and IRC is in a strong position for rapid response in the event of an outbreak. This encompasses how IRC Country Programmes can utilise and leverage existing programmes, as well as scale-up or implement new programmes. Actions in phase 2 include an analysis and identification of outbreak response components that the IRC Country Programme can contribute to. IRC's approach to Ebola-related programming is integrated across health, WASH and protection sectors, with community engagement at the centre. Country Programmes develop a strategy and budget encompassing initial rapid response interventions. The actions on the operations side for this phase focus on enhancing and strengthening IRC support functions including logistics, procurement, human resources and finance. Examples include mapping and identifying additional vendors for accommodation, transport and supplies; evaluating warehouse capacity; identifying surge support requirements; and adapting HR policies.

The Roadmap approaches readiness from a programmatic perspective, but also focuses on core operational and logistical functions. It is designed to be sequential, with Country Programmes starting at a minimum with actions in phase 1, given the focus on safety and business continuity. Whether a Country Programme completes actions in phase 2 should be determined at the country level, taking into consideration internal and external capacity to respond to Ebola, as well as existing funding opportunities to support Ebola-related programming. Actions within the Roadmap also balance the need for dedicated financial resources, which can be a key barrier to readiness efforts. Many actions can be completed without additional financial resources. However, they do require staff time and effort, which is another reason for prioritising the actions into phases.

The Roadmap is presented in the form of an Excel tool. All of the actions are presented as a checklist, separated by phase and component. Guidance is provided on who should be involved with each action, and the tools and resources relevant for

each action, including examples, are hyperlinked. There is also a status column, where Country Programmes can track actions that have been completed, are in progress or have not started. The document will auto-calculate scores, to enable progress to be monitored over time. The Roadmap also includes a template to support completion of the actions, as well as to identify additional support required by the Country Programme from the IRC Regional and Global teams. The Readiness Roadmap is accompanied by the IRC Ebola Toolkit, a series of technical and operational guidance and resources, as well as global Ebola focal points who provide support with roadmap implementation.

Lessons learned from implementation

Following the implementation of the Ebola Readiness Roadmap, the IRC observed improvements in Ebola readiness scores across all five high-risk neighbouring countries from the baseline checklist assessment in July 2019, compared to reassessment in November 2019 (an average 18% increase). Variations were noted in overall progress, as well as progress between countries, related to a number of factors and challenges:

- **Availability of tools and resources:** the Readiness Roadmap was implemented a year after the beginning of the outbreak in DRC. This affected overall readiness progress in Country Programmes as clear and focused readiness efforts started late. In addition, the Ebola toolkit was developed in parallel with the Roadmap, resulting in a delay in the availability of technical guidance, tools and resources to support early preparedness and readiness efforts. The lack of a clear framework also meant that there were variable levels of motivation to engage in readiness efforts in the first place.
- **Variations in technical support:** some Country Programmes received visits and technical support on introducing programme staff to the Roadmap and facilitating some of the key actions within it. These visits were critical in ensuring all relevant staff had a baseline understanding of Ebola and Ebola readiness efforts. Differences were observed in Ebola readiness scores between Country Programmes that received in-country visits versus purely remote technical support, where baseline knowledge was lower, often resulting in less capacity and prioritisation of readiness actions. For example, in-country technical support to IRC Tanzania resulted in improvements in Ebola readiness scores from 19% baseline to 50% in November 2019. Similarly, IRC Burundi improved Ebola readiness scores from 16% baseline to 47% in January 2020 following in-country technical support.
- **Funding:** variations were also noted in Ebola readiness scores and the level of Ebola readiness funding received. Only one of the five IRC high-risk neighbouring countries received external funding for Ebola readiness efforts (Uganda). Two received



International Rescue Committee (IRC) Health Manager Stanley Anyigu shows the IRC-run triage unit at the reception center at Kyaka II Refugee Settlement in Kyegegwa District in western Uganda.

© K Ryan at IRC

small-scale internal funds (Burundi and Tanzania). Even where funding opportunities were available, the lack of a clear framework meant that Country Programmes were not able to articulate readiness needs clearly enough, or develop proposals rapidly enough, to take advantage of them. The availability of funding affects progress in phase 2 of the Readiness Roadmap, as the focus of actions in that phase is on Ebola-related programming. The availability of funding for Ebola readiness efforts is also crucial for maintaining ongoing commitments and engagement with Ebola readiness strategies. Many of these contexts also have competing priorities related to complex humanitarian drivers and response efforts.

- **Readiness fatigue:** given the duration of the outbreak in DRC and their many competing priorities, Ebola readiness fatigue had set in across all Country Programmes. The IRC adapted approaches and support to Country Programmes to maintain interest in Ebola readiness by transitioning from bi-weekly to monthly readiness calls, developing targeted support to each country, prioritising actions that were feasible within the broader scope of each Country Programme's work and streamlining support via clear Ebola readiness focal points at country level.

Summary

The Ebola Readiness Roadmap complements the existing WHO Ebola preparedness checklist, providing specific and concrete actions for NGOs. The IRC has implemented the Readiness Roadmap in five at-risk countries (Burundi, Central African Republic, South Sudan, Tanzania and Uganda). Since implementation, all IRC Country Programmes have improved their Ebola readiness scores. The Roadmap and progress in Country Programme readiness has enabled IRC headquarters to prioritise technical support, both in-country visits and remotely, as well as the use of internal funds to support Ebola readiness. The Roadmap has served as an extremely useful tool internally to support Ebola readiness efforts and overcome challenges at the country level, and continues to play a vital part in the IRC's readiness efforts in relation to the Ebola outbreak in eastern DRC. A clear direction has also been set for how the IRC will approach Ebola readiness at the country level for future outbreaks.

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Developing a Gap Analysis tool to improve Ebola vaccine acceptance and compliance in sub-Saharan Africa

Edward Kumakech, Maurice Sadlier, Aidan Sinnott and Dan Irvine

The Ebola outbreak that began in West Africa in 2014 was unprecedented. Between January 2014 and January 2016, 28,616 confirmed, probable and suspected cases, including 11,310 deaths, were reported in Guinea, Liberia and Sierra Leone. The outbreak devastated affected populations and caused considerable disruption across the region. As of 26 December 2019, in the ongoing outbreak in the Democratic Republic of Congo (DRC), 3,366 cases (3,248 confirmed and 118 probable), including 2,227 deaths, had been recorded. The outbreak in DRC puts neighbouring countries including Uganda, Rwanda, Burundi and South Sudan on high alert should the outbreak spill over their borders.

Considerable progress has been made in relation to Ebola vaccines since 2014, and as of February 2020 a number of countries have licenced their use. However, experience has shown that, when a country does decide to deploy an Ebola vaccine, exceptional levels of demand-side (community-level) preparedness are key to ensuring its success. Reluctance and refusal are issues with all vaccines, but for an Ebola vaccine this is likely to be especially sensitive due to the fear and stigma surrounding the disease itself, alongside mistrust of government, local stakeholders and international organisations that often play a significant role in the deployment of Ebola vaccines. Effective communication and community engagement to inform, interact and create a dialogue with target populations could be the difference between high vaccine confidence, uptake and compliance and heightened vaccine concerns and mistrust, low uptake and compliance and even boycotts.

The World Health Organization (WHO)'s Global Ebola Vaccine Implementation Team (GEVIT) Practical Guidance on the Use of Ebola Vaccine in an outbreak response excels in providing guidance on supply-side preparedness for deployment. However, it doesn't cover demand-side readiness well, and thus does not enable governments or implementers to systematically assess their own readiness to deploy.

In response to this need, the Ebola Vaccine Deployment, Acceptance and Compliance (EBODAC) Consortium¹ has developed the Ebola Vaccine Communication, Community Engagement and Compliance Management (3C) Gap Analysis Tool to complement the guidance provided by GEVIT, and to enable governments, in conjunction with other stake-

holders, to assess their preparedness to deploy an Ebola vaccine from a demand-side perspective.

How the tool was developed

Development of the Ebola Vaccine 3C Gap Analysis Tool followed a consultative co-design process involving literature review, expert consultations and simulation exercises.

Literature review

The EBODAC Gap Analysis researchers² conducted a literature review examining global research, best practice, community engagement and compliance management in the context of the introduction of new vaccines; emergency vaccination programmes; and Ebola clinical trials and community-based responses. The review identified commonly used structures and layouts and the most frequent readiness themes, which were used to draft core components of vaccine deployment preparedness for assessment in the 3C Tool.

Co-production and expert consultation

The EBODAC team chose an iterative process of user-centric co-design in the development of the tool, specifically targeting on-the-ground experts with first-hand experience of Ebola outbreaks and responses, vaccine trials and community engagement.

The researchers worked in close collaboration with the ministries of health in Sierra Leone, Senegal and Uganda. Multi-disciplinary Project Steering Committees (PSCs) were set up in each country to feed in knowledge and experience, but also because their early buy-in and feedback on user preference was vital to ensuring the tool's acceptance and use once completed. Two-day co-production 'jam' events (CPJs) were held in each country in November 2018 to bring together experts, innovators, policy-makers, NGOs, community leaders and intended end-users. The CPJs and expert consultations confirmed the findings of the literature review, generated new ideas and potential solutions and flagged user preferences in the design of the tool. The research team synthesised the data gathered to produce key thematic areas for vaccine deployment preparedness to feed into a draft version of the tool.

Simulation

Key members of the health ministries in Sierra Leone, Senegal and Uganda took part in a two-day guided simulation of the use of the draft tool in September 2019. Quantitative and

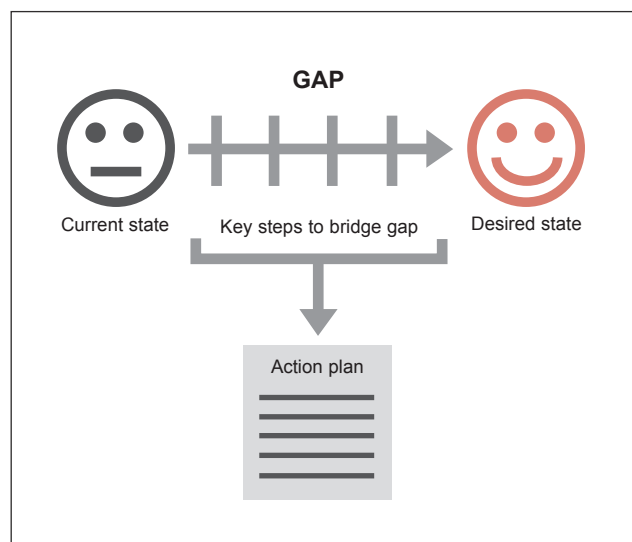
¹ The EBODAC Consortium (comprising the London School of Hygiene and Tropical Medicine, Janssen Pharmaceutical, World Vision Ireland and Grameen Foundation) was formed at the height of the Ebola outbreak in West Africa as part of Ebola vaccine development efforts, and in recognition of the complex social and cultural hurdles preventing Ebola vaccine acceptance and uptake.

² The Gap Analysis Team consisted of World Vision Research Associates based in Sierra Leone, Uganda and Senegal.

qualitative data captured during these events was reviewed, analysed and interpreted alongside other feedback, and incorporated into the final design.

What is the Ebola Vaccine 3C Gap Analysis Tool?

Figure 1: Gap analysis format



The EBODAC Gap Analysis Tool outlines potential or desired performance in communication, community engagement and compliance management. It is intended to enable a country to assess its readiness to deploy an Ebola vaccine in both non-emergency and emergency scenarios. It helps users measure their current performance against these bench-marks through a checklist and scoring system. Users can then create specific action plans or set performance targets to ‘fill the gaps’ or reach the desired end-goal. The tool has four modules:

- Module 1: Strategic 3C activities
- Module 2: Operational 3C activities
- Module 3: Integration of 3C best practices and guidelines
- Module 4: Supportive and enabling environment for 3C

Each module is broken down into three parts:

- Gap identification and scoring, which assesses readiness to implement 3C activities as countries plan for or are in the process of deploying an Ebola vaccine.
- A Prioritization Framework, which allows users to rank thematic and item-level gaps in preparedness.
- Action Planning, which allows users to analyse gaps, propose solutions and assign responsibility and timelines for putting new measures in place.

Using the Gap Analysis Tool for Ebola vaccine deployment preparedness in Uganda

A two-day simulation exercise on using the Gap Analysis Tool for Ebola vaccine deployment preparedness took place in Uganda in September 2019, involving government health officials, UN agencies, academics, NGOs and the private sector. The first day focused on using the Gap Analysis Tool to conduct an Ebola vaccine deployment preparedness assessment and gap prioritisation and action planning. On the second day, participants provided feedback to guide the EBODAC consortium in the future development of the tool.

After testing the Gap Analysis Tool, users recommended development of a shorter tool for use in emergencies or by response managers who may not have sufficient time to complete the long tool. This has since been developed and utilised to guide community engagement for the vaccine trial in the DRC. The simulation exercise identified several preparedness gaps that need to be addressed before any decision is taken to deploy an Ebola vaccine in Uganda.

Table 1: The top three priority Ebola vaccine 3C preparedness gaps identified in Uganda

Area of preparedness	Uganda's level of readiness	Priority order
Preparedness for Ebola vaccination compliance management	22%	1st
Preparedness for gender and vulnerable groups	24%	2nd
Preparedness for messaging on an Ebola vaccine	39%	3rd

Preparedness for Ebola vaccination compliance management

Vaccine compliance management concerns the systems and processes that ensure that the people targeted for vaccination actually receive it and, in the case of prime-boost vaccine regimens, that the right person receives the right vaccine at the right time. In Uganda, it was found that systems for identifying and targeting population groups to be vaccinated were inadequate, and that no system was in place for monitoring population vaccination data. The EBODAC consortium is working with the Ugandan MoH to develop and maintain a database of priority groups to be line-listed for vaccination, as well as putting procedures in place for monitoring who has and has not received the vaccine.



Piloting participants in Uganda working on the Gap Analysis Tool.

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Preparedness for gender and vulnerable groups

The simulation exercise also revealed a lack of specific attention to gender, family and vulnerable group dynamics in Uganda's current guidelines for Ebola responses. Anecdotal evidence from clinical trials in Sierra Leone points to the impact of gender inequality on vaccine trials; for example, some women were unable to participate in the trial when their husband refused to allow them to take necessary family planning measures. Teenage pregnancies were also an issue, especially in relation to disclosure as parents are required to be present for the consent process. EBODAC will be supporting technical reviews of Uganda's preparedness plans with a specific focus on addressing best practices in addressing gender, family norms, inter-spousal relations and family decision-making in communication, community engagement and compliance management plans. Attention will also be paid to identifying most vulnerable populations, including those living below the poverty line, elderly people, the disabled, migrants, refugees and other marginalised groups, to ensure that vaccine deployment guidelines take into account their specific needs.

Preparedness for messaging on an Ebola vaccine

Experience has shown that addressing community-level concerns and countering the misinformation and rumours that so often surround an Ebola response is an essential element in successful vaccine deployments. Although Uganda has previous

experience of combating Ebola, it does not have a central repository of approved messaging from previous responses to guide frontline health workers and other key stakeholders in their engagement with communities.

EBODAC has accrued extensive experience over the past four years in effective messaging to promote vaccine uptake, both in clinical trials and mass vaccine deployments. Technical reviews are under way of Ugandan MoH manuals for community and stakeholder engagement, mass public communication and interpersonal communication to ensure that key decision-makers can identify appropriate channels and audiences for messaging, and that frontline staff have relevant guidance on effective messaging when engaging with individuals and communities targeted for vaccination.

Community-based qualitative research on attitudes towards Ebola vaccines is planned for this year in six study sites across Uganda. This will explore perceptions, beliefs and attitudes towards Ebola vaccines among different population groups, and will provide baseline information for developing context-specific messages.

Conclusion

The tool is also available online at www.worldvision.ie. A shortened version has been piloted in collaboration with key stakeholders in the current Ebola outbreak response in the DRC.

The initial results of this pilot have been used to generate a targeted communication and community engagement strategy

to support a large-scale clinical trial of the Ad26.ZEBOV, MVA-BN-Filo vaccine in Goma. A country-wide assessment of DRC's general preparedness to deploy Ebola vaccines is planned for 2020.

A digital version of the Gap Analysis Tool is in development and will be completed in 2020. This will allow users to sign in to a country-specific dashboard and complete the tool online, while simultaneously providing real-time analytical feedback on 3C preparedness in an intuitive and user-friendly format.

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The evolution of a monitoring framework for the Ebola outbreak response in Kivu and Ituri provinces, 2018–2019

Emanuele Bruni, Chiara Altare, Nabil Tabbal, Silimane Ngoma and Ibrahima Socé Fall

The Ebola outbreak in North Kivu and Ituri has been one of the most difficult experienced by the Democratic Republic of Congo (DRC). The second-worst outbreak ever recorded, it has affected remote areas and urban centres bordering neighbouring countries, and has been exacerbated by a volatile context of insecurity and lack of community acceptance. The DRC government, Ministry of Health and World Health Organization (WHO) led a coordinated response by national and international partners to limit the spread of the disease and treat existing cases. Based on the experience of the outbreaks in 2014 in West Africa and in Équateur in DRC in 2018, the response was organised and implemented through the Incident Management System¹ and under the umbrella of a joint Strategic Response Plan (SRP)² encompassing activities within and beyond public health. These have been grouped in sub-pillars such as surveillance (including contact tracing); infection prevention and control (including safe burials); case management; vaccination; operational support and logistics; psycho-social support; social mobilisation, community engagement and risk communication (including anthropologic studies); laboratory and diagnostics; other basic health services; and security.

The evolution of the epidemic has been closely monitored through the extensive collection and analysis of epidemiological data to track cases, follow contacts, understand

epidemiological links, map the spread of the outbreak and identify risk factors. In parallel, a monitoring framework was developed to provide operational and strategic analysis and enable partners and donors to follow up on response outcomes. While some attempts were made to clarify the link between response activities and Ebola incidence during the West Africa outbreak, standardised operational data from outbreak responses has usually been lacking. The monitoring framework currently being used in North Kivu and Ituri therefore represents one of the first attempts to use a harmonised, multisectoral and real-time monitoring system that allows the linking of response activities to short- and medium-term impacts. This article describes the process behind the development of the monitoring framework and its key components.

The evolution of the monitoring framework for the DRC Ebola response in Kivu and Ituri

Monitoring frameworks usually comprise components that together look at inputs, outputs, outcomes and impacts. During the Ebola response, these components have been developed at different times to address operational and strategic needs. Below is a chronological narrative of this process.

Designing and implementing the monitoring framework (August–October 2018)

The first step was to define a set of key outcome/performance indicators (KPIs) to monitor how well the response was achieving its results. Three to four key indicators per sub-pillar were defined and measured on a weekly basis. These indicators were derived from the SRP and were chosen through a consultative selection from the ones used in the recently closed response in Équateur.

The second step focused on tracking the level of operationalisation of sector-specific activities against partner presence (4W

1 World Health Organization, *Emergency Response Framework* (Geneva; 2017) (<https://apps.who.int/iris/bitstream/handle/10665/258604/9789241512299-eng.pdf?sequence=1>).

2 The strategic response plans can be found here: SRP1 (www.who.int/emergencies/crises/cod/drc-ebola-disease-outbreak-response-plan-15May2018-1025.pdf); SRP2 (www.who.int/emergencies/crises/cod/drc-srp-revised-v22december2018-EN-vF.pdf?ua=1); SRP3 (www.who.int/emergencies/crises/cod/drc-ebola-srp-v20190219-en.pdf); SRP4 (www.who.int/docs/default-source/documents/drc-srp4-9august2019.pdf?sfvrsn=679e4d26_2).

mapping). Learning from the Équateur response, an activity monitoring system was put in place and adapted to improve the level of monitoring and promote accountability. Through a collaborative and consultative process, actors agreed on criteria describing necessary aspects for the implementation of each activity in terms of human resources and assets and activity implementation. For example, to measure the functionality of contact tracing, the following essential criteria needed to be in place: a system for identifying and tracking contacts; active and functional teams; a functional database; and daily validation of the contact search from a spot-check. Based on these criteria, an algorithm was developed that measured whether an activity was fully, partially or not operational. Results were translated into a colour-coded visualisation (operational = green; partially operational = yellow; non-operational = red) and shared weekly.

Initial products and Information Management Working Group (IMWG) (November–December 2018)

The need for more coordinated information-sharing encouraged the establishment of an inter-agency Information Management Working Group, comprising among others MoH, WHO, UNICEF, IFRC, CDC, Oxfam and IOM and facilitated by OCHA. The first task of the IMWG was the elaboration of an information management strategy, including the definition of the products to be published, and approaches to the visualisation of KPIs and data analysis. The group

facilitated interaction among agencies for a variety of activities, including refinement of the KPIs, the activity criteria and the algorithm, and led to the conception of new multisectoral tools such as the Infection Prevention and Control (IPC) Scorecard, which helps identify facilities in greater need of technical support to reduce infection risks. During this phase, the partners held a series of meetings to finalise the Information Management Strategy.

Digitalisation and refinement (January–May 2019)

The third major step was linked to the development of electronic tools throughout the data cycle, from data collection to dissemination of results. This included:

- Data collection: switching from paper forms to electronic data capture, using the ODK technology, for both activities and KPIs. This technical development had a major impact on the timeliness, completeness and quality of data, enabled better control of the data collection process and provided additional technical features such as geolocalisation.³
- Data analysis: data was analysed through written scripts using statistical software (Stata) and GIS soft-

³ Geolocalisation is the process of determining the location of an object or place in terms of geographical coordinates.



Two surveillance officers discussing Key Performance Indicators in the Emergency Operations Center in Beni, North Kivu.

© Nyka Alexander/WHO

ware for geographical analysis. This allowed for reproducibility of analysis and comparability of data over time (between epidemiological weeks) and space (across geographical zones).

- Data visualisation: results were visualised using Microsoft Power BI, which allowed for real-time availability. Data can be filtered for pillar, location and time, making it possible to see, for example, how KPIs evolved during a given month, or how the level of operability of a given activity differed between health zones.

The launch of the UN scale-up strategy and the declaration of a Public Health Emergency of International Concern (May 2019– February 2020)

The spike in the number of cases and a series of security incidents led to a major shift in the governance of the response with the launch of the UN scale-up strategy in May 2019. This reflected the need for a system-wide response to contain and terminate the outbreak, going well beyond a public health approach. Implementation of the scale-up strategy was directed by the Ebola Emergency Response Team (EERT), chaired by the Ebola Response Coordinator (EERC) and the WHO Assistant Director General for Regional Emergencies.

The EERT coordinated the implementation of UN support to the DRC government across five pillars addressing public health priorities (pillar 1) and an enabling environment for a safe and effective response; strengthened political engagement, security and operations (pillar 2); strengthened support to communities affected by Ebola (pillar 3); strengthened financial

planning, monitoring and reporting (pillar 4); and strengthened preparedness for surrounding countries (pillar 5). This governance shift implied OCHA officially taking over the overall coordination of information management, which had previously been shared with WHO. As a consequence, WHO's M&E activities could revolve around pillars 1 and 5, and be extended in terms of frequency (many products started to be published on a daily instead of a weekly basis); new products were designed to respond to the specific needs of WHO M&E for pillar 1 (such as daily briefs, heatmaps and security incidents monitoring); and new sectoral tools were implemented, such as the IPC scorecard (a health facility-based evaluation assessing IPC).

Following the classification of the outbreak as a Public Health Emergency of International Concern (PHEIC) in July 2019, a specific framework has been created to monitor indicators at international level in line with pillar 5.

Utilisation of the data and IM products

A variety of products designed to respond to the specific information needs of different actors are published daily (Daily brief, Heatmap, Scorecard, Incidents); weekly (activity evaluations, key performance indicators); and monthly (input and output analysis) (see Table 1). These products provide operational information to decision-makers, as well as more comprehensive information to support strategic planning.

Challenges and successes

The development and implementation of the M&E framework for the Ebola response was fraught with difficulties,

Table 1: Overview of the information management products used during the response to the Ebola outbreak in North Kivu and Ituri, 2018–2020

Focus	Activity	Products	Information type	Frequency
Daily Evolution	Activity monitoring	Daily Brief	5,579	89.7
Heatmap	Strategic and operational	Daily	96	1.5
Inputs and Service delivery	Activity monitoring	Visual	Strategic and operational	Monthly
Response	Performance monitoring	KPI	505	8.1
Dashboard	9,327		6,221	
Report	Strategic	Weekly		
Operations	Level of operationalisation, availability, quality of activities			
	KPI			
Dashboard				
Report	Strategic and operational	Weekly		
Partners Presence	Who is doing what where	3,4,5 W...	Operational	Weekly, monthly
Incidents	Monitoring of attacks, incidents, etc	Dashboard	Operational	Weekly, monthly
IPC Scorecard	Sectorial analysis	Dashboard and report	Operational	Weekly, monthly

ranging from the lack of a standardised outbreak response framework at the start that could be quickly deployed to the complexity of integrating data from multiple actors and sectors and the low appreciation of the role of M&E data in a health emergency. This led to delays in implementation and missed opportunities for more evidence-based decision-making throughout the emergency.

Even so, the progress that has been achieved is important. The establishment of the IMWG facilitated consultations among partners, and the participatory definition and revision of indicators, criteria and data collection tools increased the acceptability of the system. Efforts to streamline the data cycle through the development and implementation of electronic data capture tools, statistical scripts and visualisation dashboards allowed for real-time analysis and visualisation. The toolkit that has been designed and piloted represents an excellent starting point for future adaptations in other outbreaks.

Conclusion

In the context of outbreaks in disrupted health systems,⁴ a package of health indicators monitoring the performance and status of implementation of multilevel interventions⁵ can identify the strengths and weaknesses of the response, inform decision-making, refine improvement strategies,

4 WHO, *Analysing Disrupted Health Sectors: A Modular Manual*, 2009 (www.who.int/hac/techguidance/tools/disrupted_sectors/en/).

provide lessons learned and improve accountability to affected populations. The implementation of a multisectoral and digitalised monitoring framework has helped raise awareness among response stakeholders of the added value of monitoring inputs, outputs and the status of activities, as well as performance indicators, to complement epidemiological data. The monitoring and evaluation framework has increasingly been incorporated into decision-making at operational, strategic and planning levels, and has become an integral component of strategic response plans. Inter-agency efforts are now needed to ensure that response planning for future health emergencies builds on this experience, and that a performance-oriented and monitoring-driven approach is adopted from the outset of an emergency.

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5 Emanuele Bruni et al., A Package for Monitoring Operational Indicators of the Response to the Outbreak of Ebola Virus Disease in the Democratic Republic of the Congo, *Weekly Epidemiological Record*, 94 (3), 2019 (<https://apps.who.int/iris/handle/10665/279759>).

Security and access in the DRC: implementing an acceptance strategy in the Ebola response

Adelicia Fairbanks

Responders to the Ebola outbreak in eastern Democratic Republic of Congo (DRC) face tremendous challenges in halting the spread of infection, not the least of which is insecurity. Insecurity Insight reports that, between January and November 2019, there were more than 400 attacks against response actors, including threats, abductions and arson. Since January 2019, at least 20 health workers have been killed.¹ According to the UN, the majority of security incidents affecting Ebola responders were linked to armed conflict, community resistance and civil unrest.

Organised attacks, deteriorating security and increased distrust of response actors by local community members have in the past coincided with a rise in Ebola cases and increased transmission in the DRC. In this context, response actors must implement effective humanitarian security risk management measures to protect themselves, as well as

to effectively respond to the epidemic. However, strategic security risk management approaches appear to be largely absent from the response, in part due to a failure by leading response agencies to recognise the DRC as a complex humanitarian emergency, as well as a public health crisis.

This article looks at the implications of this narrow approach and the security challenges response actors face in the DRC, and aims to demonstrate how a humanitarian security risk management approach that focuses on the prevention of security incidents through the adoption of an acceptance security strategy can improve the security and access of responding agencies. It draws on existing literature, as well as interviews with actors involved in the response.

The context

Eastern DRC has been plagued by armed conflict for over 20 years. It hosts the world's largest UN peacekeeping force and a myriad of non-state armed groups with varied and

1 Data compiled by Insecurity Insight on security incident information within the DRC Ebola response is accessible here: <http://bit.ly/38oNumi>.



People who have been in touch with someone who has been infected, receive food aid, in order for the humanitarian community to monitor them during four weeks

© World Bank/Vincent Tremeau

unclear motivations. The conflict has resulted in substantial displacement: North Kivu has an estimated 2.5 million displaced people and refugees. Men, women, girls and boys are victims of violence, sexual assault, forced conscription, extortion and crime. The Kivu Security Tracker shows that, in North Kivu between April 2017 and February 2020, 2,207 people were killed and 1,242 abducted. According to the Aid Worker Security Database, there were 41 major incidents directly affecting aid workers in the DRC between January 2018 and January 2020; of the 80 reported victims, 77 were national staff.

Lack of law and order in the region is compounded by weak government presence. Local communities rely on NGOs and other civil society groups to provide basic services such as education and healthcare. Widespread corruption and poor infrastructure – including no centralised electricity and unpaved roads – severely affect livelihoods and incomes. Community trust in the government is extremely low, and this is exacerbated by a lack of clear boundaries between the Congolese national military and non-state armed groups. Soldiers guarding a Congolese military checkpoint during the day can be found guarding an armed group's checkpoint at night.

Security challenges

Response actors in the DRC face two overarching security challenges: insecurity resulting from attacks by non-state

armed groups, and community mistrust and resistance. The UN reports 178 security incidents stemming from community resistance to Ebola response activities between August 2018 and May 2019. Data on community perceptions collected through feedback mechanisms indicates that a large number of local community members believe that Ebola is a scheme of the government or others, and that Ebola is an organised business.²

Community mistrust is exacerbated by the consequences of a narrowly focused public health response. Communication with communities is mostly one-sided – focused more on informing rather than asking and answering questions and addressing concerns. Response actors have also been known to enter communities, escorted by armed guards, to retrieve bodies without speaking to community members. Many local staff members lack training in effective community engagement.

The other major challenge is insecurity resulting from attacks by non-state armed groups. Two attacks carried out by rebel militia in November 2019 killed four responders and injured five others. These are just two examples of attacks perpetrated by armed groups against health facilities and response personnel.

² For more information, see the latest Social Science in Humanitarian Action 'Social science and behavioural data compilation' for the DRC Ebola outbreak, available here: www.socialscienceinaction.org/resources/social-science-behavioural-data-compilation-5-ebola-outbreak-eastern-drc-september-november-2019/.

Security risk management in the DRC: an acceptance approach

Response actors must implement effective humanitarian security risk management in the DRC to protect themselves and reduce the spread of infection. Yet security risk management is often seen as merely the implementation of day-to-day security measures, such as curfews, travel restrictions, the use of armed escorts and the management of security incidents. This oversimplification of security risk management lacks a coherent overall strategy, and fails to take account of the broader implications of activities undertaken in the name of security, such as the use of armed escorts.

An appropriate approach to humanitarian security risk management includes a strategic analysis of measures to prevent security incidents from occurring in the first place. Central to this is the adoption of a humanitarian security strategy. In the DRC, where conflict is ever-present and insecurity is at least partially a function of local actor mistrust, an acceptance approach to security is pivotal. Acceptance involves obtaining the approval, consent and cooperation of communities, local authorities and other stakeholders. In the DRC, this means implementing a security risk management framework that is guided by an over-arching acceptance strategy, within which the security measures adopted aim to foster local trust and ownership of the response.

Addressing all humanitarian needs

A broader approach to the humanitarian crisis in eastern DRC – one not solely focused on Ebola – is essential to improve community acceptance. Arguing for greater community engagement in the Ebola response, Vinh-Min Nguyen, a medical team leader for Médecins Sans Frontières (MSF) in North Kivu, shared the positive impact his team had had on community acceptance by treating medical conditions beyond Ebola.³ This broader approach reassured local communities that their needs were just as important to responders as addressing the risk that Ebola poses in the DRC and at a global level.

Adhering to humanitarian principles

Central to obtaining acceptance is clarifying the role and motivation of response actors. This means adhering to a standard code of conduct, such as the core humanitarian principles of neutrality, impartiality and independence. Response actors should focus on engaging in community dialogue to emphasise their neutral position within the conflict and the independence of the response from broader political and financial interests, and clarify that the primary purpose of the response is to help affected people. Perceptions can be more important than intentions when it comes to obtaining acceptance.

3 V. Nguyen, 'An Epidemic of Suspicion: Ebola and Violence in the DRC', *New England Journal of Medicine*, 380, 2019.

Restricting the use of armed escorts

In conflict environments such as the DRC, civil-military coordination can exacerbate the relationship between local actors – such as community leaders, community members and non-state armed groups – and response organisations. Coordination of this kind – while often perceived as important in ensuring the security of response actors – can blur identities between responders and parties to the conflict and result in the direct targeting of response actors by communities and armed groups. The presence of armed escorts during surveillance activities in eastern DRC has damaged perceptions of response actors among local communities, potentially contributing to the overall climate of insecurity affecting the response and limiting access to affected communities. The use of armed escorts should, therefore, be carefully considered as part of a broader security strategy in the DRC.

Adopting common rules of engagement

It can take weeks for organisations to negotiate access to communities, but these efforts can be thwarted if other organisations adopt different rules of engagement, for instance arriving in the same community, uninvited and accompanied by an armed escort. Incidents of this nature are not uncommon in the DRC and serve to further erode the community's perception of the overall response. To address this risk, the United Nations Children's Fund (UNICEF) and community engagement partners are supporting the Congolese Ministry of Health (MoH) in rolling out principles of community engagement. Adherence to these principles by all response organisations is imperative to regain community trust in the response, and to improve the security of operations.

Supporting dialogue

Dialogue with communities and other stakeholders on all aspects of the response is crucial in fostering trusting relationships. This includes gathering data on local perceptions, needs and concerns and addressing them. Multiple actors in the DRC are carrying out comprehensive feedback activities to improve community engagement.⁴ Several actors are also carrying out social science research to improve responders' understanding of community and individual behaviours, beliefs and practices (particularly in relation to health) in order to adapt response interventions. The MoH-led and UNICEF-supported Cellule Analyses – Science Sociales (CASS)⁵ and the Social Science in Humanitarian Action Platform, for example, conduct social science research and provide publicly available insights, analysis and advice, which response actors can use to inform their security risk assessments and security strategies and measures, and to adapt their response activities and programming.

4 For example the IFRC and the Communications Commission.

5 All CASS information and research is checked by the Congolese Ministry of Health and UNICEF, and is accessible online at https://drive.google.com/drive/folders/1H3JkO3YhEU5TT99-Lk_sAwXRuE9UUKMY.

Conclusion

The Ebola outbreak in eastern DRC is part of a broader complex emergency, where historical and present-day conflict, a weak national health system and other humanitarian concerns interact to intensify the spread of Ebola and exacerbate other humanitarian needs. The World Health Organization (WHO) has acknowledged that the Ebola response must go beyond the public health framework and should take into account broader humanitarian needs, security issues and community engagement. WHO also recognises that one of the most persistent and severe threats to the Ebola response is the insecurity caused by underlying social and political tensions. A humanitarian security risk management lens, which focuses on prevention and the adoption of an acceptance approach, can effectively address these security challenges.

As the world faces increasingly complex emergencies where public health crises interact with conflict dynamics, fragile political, social and economic institutions and broader humanitarian needs, a fundamental shift in approach is needed by health responders. Central to this is a greater understanding of the role that effective humanitarian security risk management can play in a complex emergency of this kind, to improve not only the security of responders, but also their access to communities and the effectiveness of response activities.

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