

Social Science in Humanitarian Action

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Key considerations: changing behaviours & care-seeking practices in the *Grand Nord*, North Kivu, DRC

This brief summarises key considerations concerning changes in behaviour and care-seeking practices in the context of the outbreak of Ebola in the *Grand Nord* of North Kivu, DRC, September 2018. Further participatory enquiry should be undertaken, but given ongoing transmission, conveying key considerations and immediate recommendations related to community engagement have been prioritised.

This brief is based on the input of expert advisers in close communication with networks of contacts in North Kivu (community leaders, religious leaders, local authorities, clinicians, health workers, NGO staff, community members, local researchers etc). It builds on a rapid review of existing published and grey literature, experience of previous Ebola outbreaks in the DRC and elsewhere, and informal discussions with colleagues from UNICEF, WHO, IFRC, Oxfam, GOARN Social Science Group and others.

Prior to finalisation, it was reviewed by expert advisers from Anthrologica, Institute of Development Studies, Harvard Academy for International and Area Studies, University of Basel, University of Notre Dame, University of Ghent, Pole Institute, University of Florida, CNRS-MNHN, Musée de l'Homme Paris, University of Sussex and risk communication and community engagement colleagues from UNICEF, WHO and CDC. The views expressed in the document are not unanimously held by all reviewers. Responsibility for this brief lies with the Social Science in Humanitarian Action Platform (SSHAP).

Recommendations

Community engagement

- **Strengthen community dialogue:** Communities in the *Grand Nord* consistently demonstrate their need for more detailed information that goes beyond the repetition of basic messaging. This should be interpreted as a positive indicator of engagement that the response should harness. Although many community engagement activities are being conducted across the *Grand Nord*, the flow of information remains largely one-directional: from the response to affected communities. It is reported that when community meetings are held, there is normally little opportunity for community participation, for discussion or for attendees to ask questions or offer solutions. When communities feel that they lack sufficient information and decision-making power or are unable to adhere to prescribed behaviours, frustrations can quickly develop. In the context of the *Grand Nord*, violence is often the normal recourse action when frustrations become too great. There must be a shift to meaningful community dialogue that primarily listens to the affected communities and facilitates the two-way exchange of information. This is essential as it a) fosters active participation and gives people agency; and b) can provide the response with operationally useful information. Facilitating true dialogue requires specific skills and expertise that should be strengthened across the response.
- **Shift to community feedback:** It is recommended that the term 'community feedback' be adopted by the response and terms based on 'rumours' avoided (e.g. rumour tracking). Rumours imply inherently negative and false information and are only one type of information that circulates at the community level although they do convey particular meaning. 'Community feedback' is constructive, conveys agency and trust and incorporates different types of information (both positive and negative).
- **Analyse and operationalise community feedback:** Agencies are trying to gather and analyse community feedback more systematically but this is difficult to do in a timely and efficient way. Further technical support and resources should be dedicated to ensure community feedback can be rapidly collated and analysed, and the analysis used to guide decisions about interventions. Community feedback should be directly reported to the communication commission, but should also be integrated and operationalised across other pillars within the response through the IMS and other relevant structures.
- **Analyse and operationalise survey data:** It is important to further understand specific practices associated with health-seeking behaviour and care-giving amongst affected communities and how these may change over the duration of the response. A knowledge, attitude and practices (KAP) survey conducted one week after the Ebola outbreak was declared in North Kivu (August 2018) by the Communication Commission and supported by UNICEF indicated that although the level of awareness about Ebola was high amongst the people surveyed in Beni and Mangina, the level of knowledge about Ebola was low. The Commission's second KAP is being conducted in September and the comparison of these data sets should provide useful information about changes in knowledge and practices over the first phase of the outbreak. Further information about this KAP is available from Jonathan Shadid (jdshadid@unicef.org). The Harvard Humanitarian Initiative is also conducting a survey in Beni, Butembo and Goma. Data and analysis will be available from 22 September and should be quickly reviewed by response agencies and used as an evidence base to guide interventions. Further information about the HHI survey is available from Patrick Vinck (pvinck@hsph.harvard.edu). Good quality qualitative data that can be triangulated with the KAP data is needed to provide a more granular and nuanced understanding of the root causes of certain behaviours.
- **Be participatory:** Community engagement activities should be made as participatory as possible. Action-based workshops that use 'edutainment' methods and role-play have been reported to be well received with attendees displaying a higher-level of sustained engagement. This is particularly important when engaging low-literacy populations who are only conversant in local languages, and to ensure a gender-sensitive approach. Rather than just instructing people about what to do in a didactic manner, explanations must be given about why these behaviours are important and a greater level of detail provided. Different modes of community engagement that tap into a variety of local platforms should be employed strategically and should be evaluated so that limited resources can be channeled to have the greatest impact.

- **Work through local structures:** Greater visibility of trusted local authorities and community leaders is needed to stem misinformation and fear; to encourage community members to report symptoms, seek timely care and alert burial teams; to obtain support and feedback from communities; and to facilitate the access of response teams into affected areas. It is critical that local personnel and local structures be remunerated and resourced appropriately and that recruitment processes are made transparent. There are numerous reports that local health workers and vaccinators are being paid significantly less than personnel coming from Kinshasa to work in the response in North Kivu. There are also concerns that elevated rates of pay of local response staff by international agencies will be destabilising in the longer-term. Whether this is the case or not, widespread perceptions of inequitable pay, corruption and nepotism (with some local authorities, including local chiefs, allocating safe but well-paid work to their immediate network) are fuelling resentment and frustration and should be directly addressed and resolved.
- **Engagement with armed groups:** The health-seeking practices of armed groups can increase insecurity and heighten the risk of transmission. Further engagement with armed groups is needed to ascertain their level of knowledge about Ebola, how they may be protecting themselves, and how they are seeking care for symptoms that may / may not be signs of Ebola. It is recommended that a specific strategy be developed for engaging armed groups.

Care-seeking practices

- **Demystify Ebola Treatment Centres (ETCs):** It has been well documented that the design of ETCs, the level of community engagement, the role of families and strong communication channels can help demystify ETCs and position them as places of good quality care where there is hope of treatment and survival. Activities that directly seek to reduce widespread fears associated with ETCs, isolation and the sense of the unknown must be quickly scaled-up (detailed below). It is understood that survivors and their 'testimonies' are being incorporated into engagement strategies in the Grand Nord, but care for their health and wellbeing must be paramount.
- **Encourage early presentation and reporting:** Communities are reported to be increasingly hesitant to present at health facilities because they are concerned about contracting Ebola whilst presenting for another illness and because of fear associated with being sent to an ETC. Demystifying ETCs and introducing triage procedures into health facilities may encourage early reporting and presentation of signs and symptoms, but community engagement efforts must also seek to directly rebuild trust in health structures and health professionals. The competencies of health workers (including those at health posts) must be supported to ensure they are confident to recognise the signs and symptoms of Ebola and act accordingly (implementing triage and infection prevention control procedures, isolating the patient if necessary, liaising with their local ETC or response team, calling for an SDB team or investigative team should the patient die). Community engagement activities should stress that anybody with potential signs or symptoms of Ebola should go directly to their nearest ETC.
- **Vaccination:** In general, the Ebola vaccine appears to have been well accepted with a high uptake rate amongst those who are eligible. Some community members, however, continue to express concerns that it is a lethal injection and that it will give a person Ebola. The notion that the vaccine can prevent women from becoming pregnant and cause sterility has also been recently reported in different communities in the Grand Nord. Engagement strategies must address these concerns whilst emphasising that the vaccine is not a 'magic bullet' and stressing why protective behaviours and public health control mechanisms must be continued despite vaccination.
- **Homecare:** In remote and insecure areas that responders cannot access and from where patients are unlikely to be able to present for care, communities must be supported to provide safe homecare. This is both complex and controversial, but may be a feasible option given the context of the Grand Nord and should build on local self-protection mechanisms. It will entail training being cascaded to community members (potentially through the use of short videos) and the sustained provision of appropriate resources and protective equipment. Remote supportive supervision could be provided via WhatsApp (voice calls, text and video messaging).

Adoption of protective behaviours

- **Hand-washing:** If communities are to sustain hand-washing practices, necessary equipment must be equitably distributed and basic supplies maintained. The provision of material goods needs to be well negotiated at the community level to avoid conflict. When communities are unable to follow preventative measures due to a lack of resources, levels of frustration and associated fear develop. At checkpoints, all travellers should be supported to use hand-washing stations that are in place, including minibus passengers and motorbike taxi drivers who may not be able to dismount due to heavy loads. How this is best done needs to be identified at the local level. It may also be beneficial to explain that behaviours such as hand-washing will have a positive impact on persistent health issues other than Ebola, e.g. to help stop the spread of cholera.
- **Burial practices:** Although communities appear to be largely accepting of safe and dignified burial (SDB) practices, challenges have been reported due to the length of time between when a family calls for a burial team and when they arrive. To mitigate the frustration this causes and the associated negativity towards the response teams, communities should be given clear information about how long the team will take to arrive and direction about what families can constructively do during this period. It must also be emphasised that although communities may appear to accept SDB at the time, the impact of not being able to perform a 'proper' burial has longer-term significance and affected communities must be offered ongoing psychosocial support if SDB is perceived not to be a 'proper' burial.
- **Dietary changes:** It has been reported that people have changed their diets to stop eating meat (beef, goat, etc.). Clarification should be given that eating meat is not prohibited, particularly as this may have a severe impact on communities that already have nutrient deficiencies.
- **Physical contact:** Concerns about intimate physical contact are frequently being raised by community members in terms of 'maternal love' and 'touching one's partner' and more broadly in terms of future sexual reproductive health (particularly expressed by youth). These questions and concerns should be directly addressed in community engagement activities. Given new research about the ongoing risk of sexual transmission (based on longitudinal studies after the West Africa Ebola epidemic), communication must be kept updated to be as accurate as possible.

Care-seeking practices

- **Multiple pathways of care:** Evidence shows that care-seeking practices are not static but shift and evolve in response to immediate conditions. Communities are pragmatic: both individual and collective behaviours are adjusted to protect a person's own health and that of their household and community. People will try multiple courses of action in an effort to effect a cure, and will seek different types of care either consecutively or in parallel (including biomedicine, self-medication and local healing practices). When they understand the risk of transmission, communities are best placed to suggest acceptable modifications to local care practices and health-seeking behaviours.
- **Presentation at health facilities:** Despite the weak health system and persistent challenges in accessing health facilities, high levels of trust in health services and health workers were reported in the Grand Nord prior to the Ebola outbreak, particularly in urban centres. Still, late presentation at health facilities, when symptoms were well advanced, was common practice prior to Ebola. In the earlier phase of the response in Beni territory, it was reported that people who engaged with health services were more likely to present at a health facility with symptoms given that Ebola was 'new' and 'unknown': *'People understand that it [Ebola] is a very dangerous disease, so they are less likely to use traditional or natural medicine, but to go directly to the hospital'*. However, lower levels of attendance have recently been reported in many health zones and communities are increasingly fearful to present at health facilities. The most frequently provided reasons included: *'fear of being told you have Ebola when you have something else'* (such as malaria); *'fear of getting Ebola when are at the health facility'* (from health workers, other patients, or being infected on purpose); *'fear of being sent or kidnapped to the Ebola treatment centre'*. Given the limited infection prevention control (IPC) measures that were in place and the limited capacity of health workers to identify and respond to signs and symptoms of Ebola at the start of the outbreak, fear of infection at a health facility and diminished trust in health workers was not unfounded.
- **Fear of ETCs:** Widespread distrust and fear of ETCs prevents communities from reporting symptoms and presenting for care. The perception that everybody who goes to an ETC *'will surely die'* and the joint fears of isolation and the unknown are clearly articulated in community narratives. UNICEF has recently reported holding meetings with community leaders to introduce them to ETCs. Such consultations proved effective in the West Africa outbreak when community members as well as leaders were given 'tours of the ETC green zones'. Similarly, ETC staff undertook community visits during which they were supported to explain ETC activities and to listen to and address questions and concerns raised by community members. It has been suggested that short videos documenting a 'virtual tour' of an ETC and highlighting patient care may be used alongside other community engagement activities. The importance of family care and of not being isolated should not be underestimated. In the response to the Ebola outbreak in Équateur (2018), ALIMA reported using transparent walls in their ETC to enable family members to 'see' what was happening, and set up a 'family hotel' next to the ETC where family members were lodged whilst the patient was being treated. It is imperative that channels of communication between ETCs and communities are improved and that family members are kept up-to-date about the condition of their relative. Guidance is already in place to ensure the family of a patient receives psychosocial counseling. Most importantly, the perception that anybody who is admitted to an ETC will die must be replaced by the perception of an ETC as a safe facility that offers lifesaving treatment and therapeutics. In other outbreaks, survivors have played an important role in bringing hope to communities, providing testimonies about patient care and proving, through their own experience, that people can survive.
- **Alternative source of care:** Communities continue to use alternative sources of care including self-medication, pharmacies and traditional healers, often for pragmatic reasons such as easier access, less direct and in-direct costs and shorter waiting times than those associated with health facilities. The response has been proactive in engaging alternative frontline providers of care in North Kivu. This is a welcome development compared with other outbreaks as they can be positive agents for behaviour change at the community level (leading by example and conveying key health information) and can provide real-time intelligence to surveillance and contact tracing teams. The WHO reported to be mapping traditional healers in the Grand Nord and providing them with information regarding signs and symptoms of Ebola and how to refer a patient, and to offer them vaccination. Further details are not known, but the mapping should aim to distinguish between different types of healers / local practitioners and record the types of intervention they offer. In North Kivu, as elsewhere in the DRC, it is important to determine the cause of illness, and local healers are often consulted in this regard. It should be noted, however, that even if the cause is thought to be a curse or witchcraft, this does not necessarily preclude seeking biomedical care.
- **Church and INGOs:** The protestant church has a long tradition of missionary and church involvement in providing healthcare to communities in Kivu. The Oicha General Hospital, for example, is run by the CECA 20 Protestant denomination and is reported to have a good reputation. Contributions from wealthy businessmen based in Butembo have further strengthened healthcare institutions in some areas of the Grand Nord, although not in Mangina. International relief organisations have also been an important source of healthcare. Médecins Sans Frontières (MSF), for example, has provided health services in collaboration with the Ministry of Health in North Kivu for many years, whilst other NGOs and faith-based organisations have worked through mobile teams to provide care for populations who cannot access government health facilities due to insecurity issues and mobility. The extent to which these teams are still operational and may be being utilised by communities during the Ebola outbreak is unclear.
- **Politics and insecurity:** The complexity of the political situation, conflict and insecurity in the Grand Nord have been well documented and form a dynamic backdrop to how communities are perceiving the Ebola outbreak. The view that Ebola is a continuation of the threat of the mass killings and was 'brought' to Beni (from Equateur) to continue the insecurity in the Grand Nord is widespread and continues to circulate in the local media. In recent online articles and radio interviews, for example, it has been suggested that Ebola was 'manufactured' for 'medical terrorism'. There is a localised narrative that suggests Ebola is an issue (or phenomenon) of Mangina or the Grand Nord rather than a broader public health concern.
- **Influence of armed groups:** Before the current Ebola outbreak, access to healthcare was highly challenging for communities directly affected by the ongoing conflict and many health centres in the most insecure and volatile areas had closed. Hospitals and health centres across Beni territory were subject to attacks from armed groups seeking medical supplies, and a number of doctors around Beni (including international personnel) had been kidnapped to provide medical treatment to group members. The health system (both structures and personnel) is reported to be embroiled in local militia politics, land conflicts and ethnic disputes, particularly around Bambuba-Kisiki and Banande-Kainama *groupements*. As a result, the insecurity and killings around Beni

coincided with the forced transfer and intimidation of doctors from the Oicha hospital, and the hospital at Eringeti was the subject of a serious attack in late 2015. The health-seeking practices of armed groups can increase insecurity and heighten the risk of transmission. Further engagement with armed groups is needed to ascertain their level of knowledge about Ebola, how they may be protecting themselves, and how they are seeking care for symptoms that may / may not be signs of Ebola. It has been suggested that members of armed groups may cross the border to seek treatment at trusted hospitals such as the hospital in Bundibugyo (Uganda), although again, further investigation is required.

Changing behaviours

- **Burial practices:** Although communities appear to be largely accepting of SDB practices, challenges have been reported due to the length of time between when a family calls for a burial team and when they arrive. At the time of writing, there are 10 Red Cross SDB teams that have been trained and are operational in Beni (2), Mangina (4), Butembo (2), Bunia (1) and Mambasa (1). Given the large areas these teams must cover, a period between when the team is notified and when they can arrive at the deceased's house is to be expected. The recent establishment of the SDB sub-commission in North Kivu should help strengthen this pillar of the response.
- **Hand-washing:** Frequent hand-washing is consistently observed across the Grand Nord where hand-washing stations and chlorination points have been set up and water and soap provided. In general, there is a high level of awareness about hand-washing, and in Goma (which is not currently affected by the outbreak), customers are being provided with hand sanitiser by many restaurants. In areas of the Grand Nord where equipment has not been distributed, however, it is reported that some communities are not able to practise hand-washing due to limited resources. The price of disinfectant sold in markets has risen rapidly over the last few weeks, and in areas where mobility is restricted (due to both Ebola and insecurity), people are reported to be using ashes instead of soap (e.g. villagers in Mbalako health zone including Kantine, Ngoyo, Kyanzaba and Bingo who cannot travel to Mambingi to buy soap). At checkpoints, many motorbike taxi drivers do not dismount to wash their hands for fear their heavily loaded bikes will fall over. Similarly, many passengers travelling in *camions* (crowded local minibuses) do not leave the bus to wash their hands. A lack of drinking water has been reported in some areas, although water storage devices have been installed in Beni and Mangina.
- **Limited physical contact:** Across the Grand Nord and in other areas of North Kivu (e.g. in Goma), it is widely observed that people have stopped shaking hands or embracing. People now greet each other by waving, touching elbows, tapping the inside arch of their feet and jokingly 'shaking' or 'bumping' hips or buttocks. Vendors are using plastic bags as makeshift protective gear to pass out items such as bottled beer or peanuts, and it has been reported that barbers are wearing gloves and disinfecting their scissors and razors before shaving a client's head. Concerns about intimate physical contact are frequently being raised by community members in terms of 'maternal love' and 'touching one's partner'.
- **Food and diet:** Many people have started to avoid sharing food and drink. Instead of friends drinking locally produced alcohol from the same bottle, some people now bring their own glass or cup. People have also been observed to be preparing food using chlorinated water, but it was noted that this changes the taste of food and makes it 'bitter'. It has also been reported that some people have changed their diets to stop eating meat (beef, goat, etc.). This may be a result of messaging about avoiding bushmeat, but further investigation is required.
- **Church attendance:** It was reported that some people have started to stay at home rather than attend church as a way of avoiding large gatherings. At church, modifications have been made during services to reduce physical contact: people no longer shake hands, communion has stopped or been amended so that the congregation does not share the same cup; and it was reported that some churches have stopped conducting baptisms. Church and religious leaders maintain close links with their parishioners and smaller prayer groups continue to meet.
- **Movement of people:** People continue to be highly mobile, moving in and out of the Grand Nord, across the affected territories and between the urban centres and rural areas. Despite this level of 'normal' mobility, it is reported that communities are highly alert and monitor who comes into their areas. Communities (e.g. in Ituri) remain concerned that people thought to be fleeing Ebola in Beni and Mangina may transmit the disease to other areas. This has been challenging for contact tracing as mobile response teams are also seen to bring heightened risk. Community consultations have been required to overcome the refusal of some communities to allow contact tracing, but the fact that communities are watchful of who comes into their areas is inherently positive, particularly given the backdrop of ongoing insecurity.
- **School attendance:** The start of the new school year (early September) has created anxieties relating to the spread of Ebola. Some parents have suggested that they will not allow their children to return to school for fear of infection, and the teacher's union (*Syndicat des Enseignants du Congo, SYECO*) has called for all school children and teachers to be vaccinated prior to the start of the school year. UNICEF is engaging schools (school heads, parents associations) in the affected health zones to put protection mechanisms in place. Teachers should be provided with basic psychosocial skills to support their pupils, and school children should be engaged using appropriate participatory methods to teach them about the disease, how to protect themselves and their families, and about treatment and vaccination.

Contacts

If you have a direct request concerning the response to Ebola in the DRC, regarding a brief, tools, additional technical expertise or remote analysis, or should you like to be considered for the network of advisers, please contact the Social Science in Humanitarian Action Platform by emailing Juliet Bedford (julietbedford@anthrologica.com) and Santiago Ripoll (s.ripoll@ids.ac.uk).

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