Social Science in Humanitarian Action

Social Science in Epidemics: Ebola Virus Disease Lessons Learned

Lessons Learned

This report is the second instalment of the 'Social Science in Epidemics' series, commissioned by the USAID Office of U.S. Foreign Direct Assistance (OFDA). In this series past outbreaks are reviewed in order to identify social science 'entry points' for emergency interventions and preparedness activities. The aim is to determine tangible ways to address the social, political and economic dynamics of epidemics; and to ensure that interventions build on the social and cultural resources of the communities they aim to support. This report explores lessons about the social dimensions of past and recent Ebola epidemics.

In Turanga, Goma, North Kivu province, eastern Democratic Republic of the Congo, a community engagement team member speaks about Ebola with Kavira Esther and her family at their home.
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How to read this report:
this document provides an in-depth review of evidence on different aspects of Ebola epidemics. It is organised into the following categories, and readers with a specialist interest can skip to the relevant category:

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Lessons Learned

In each category social science lessons learned are highlighted followed by a series of recommendations. Recommendations are divided into those that are operational, i.e. they are immediately applicable in the event of an outbreak, and those that are orientated towards longer term capacity building. This report will provide the basis for a set of programme-oriented case studies and operational tools that will be published in 2019.

This report focuses on the lessons learned primarily from (i) the 2014-2016 West African epidemic that killed over 11,000 people in Guinea, Sierra Leone and Liberia, (ii) the outbreak in North Kivu and Ituri Province in North Kivu (August 2018 - ongoing), (iii) the outbreak in Equateur Province in the Democratic Republic of Congo (May- July 2018), (iv) historical outbreaks in Congo such as Kikwit 1995, Kasai 2007 and Bas-Uele 2017, and (v) outbreaks in Uganda in 2000-01 and 2012. Infection in these outbreaks was by ZEBOV, with the exception of Uganda which was by SUDV.[1] The Zaire Ebola virus species ZEBOV, has high case-fatality rates, ranging from 25% to 90% (Chandler, Fairhead et al. 2015, WHO 2018).

1. Emergence

Trends in deforestation, land-change (e.g. conversion of forest to palm plantation, agriculture, to mining) and urbanisation are creating new opportunities for Ebola emergence. Ebola host reservoirs are (thought to be) fruit bats, and primates are often infected by eating fruits previously masticated by bats (Gonzalez, Pourrut et al. 2007). The exposure to infected bats and primates or their carcasses enables human infection. From the current evidence, we can say that exposure to sick or dead animals is how the majority of outbreaks emerge. Exposure to bats is suspected as a pathway of transmission, yet there is no real evidence yet for bat-to- human transmission. Often this pathway is speculated upon when no bushmeat contact is found in the epidemiological research. Some authors report a higher likelihood of zoonotic spillover to humans due to changes in migration patterns of host species (influenced by climate change), as well as increased human pressure on the forest belt of Central Africa: resulting in higher prevalence within reservoir species and higher likelihood of human contacts with infected hosts (Hassell, Begon et al. 2017: 58). The science of emergence is contested, since the ecological pathways of the virus from host to primates are still the subject of research. Therefore, trends in emergence need to be viewed critically.

Higher human pressures on the forest have been linked to poverty and inequality (ibid.). An increase in hunting pressure is also reported in areas with increased population and road access (Ziegler, Fa et al. 2016) and is fuelled by the growth of bushmeat markets in Central African cities (Fa, Olivero et al. 2016).

Ebola emergence in forest regions is shaped by the interplay of climatic, social-economic and ecological dynamics. These dynamics are, like neural networks in the brain or weather systems, non-linear, and hence Ebola disease emergence is complex and highly unpredictable (Leach, Scoones et al. 2010). Interpretations of trends in deforestation, and therefore habitat change and the relative increase in people's interactions with bats, have been misleading in the past with forest loss being overestimated and blamed on local people (Fairhead and Leach 1998). Although deforestation and urbanisation may well have accelerated in recent decades, it is important not to overlook long-term interactions between people, forests, and bats. Further, local people are very knowledgeable about changes in the forest and its wildlife and studies of emergence have not always capitalised on this local expertise.

Bushmeat consumption can potentially be a source of Ebola infection. The virus stays active in the carcass for at least four days. Infection can occur when a person touches the carcass of an infected dead animal during hunting or butchering. However, cooking kills the virus. In Ebola outbreaks, the initial emphasis of the response has often been put on 'zoonotic spillover' through bushmeat consumption, yet in reality, the most important form of transmission is direct person-to-person contact.[2] Once the outbreak has occurred, how

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[1] Species of the Filoviridae with the capacity to infect humans are Zaire Ebolavirus (ZEBOV) Sudan Ebolavirus (SUDV), Cote d'Ivoire Ebolavirus, Bundibugyo Ebolavirus (BDBV) and Tai Forest Ebolavirus.

[2] Unlike in Influenza, often the genetic variation and species jump ('zoonotic spillover') to humans only happens once in an Ebola outbreak, and from that initial human infection, all the others branch out. Marburg virus disease, caused by another filovirus is different in that the relative weight of zoonotic transmission (multiple infections from animals to humans rather than a single one) vs. human-to-human is higher (WHO R&D Blueprint).

Lessons Learned

the outbreak started (e.g. through direct contact with bushmeat or its consumption) is relatively of little importance to how the disease is perpetuated, which is through human-to-human transmission. Hence, zoonotic spillover from contact or consumption of bushmeat and human-to-human transmission should be clearly distinguished in response and preparedness. Often, bushmeat markets have been portrayed by media and communities as the culprit, with Ebola messaging focusing on curtailing the consumption of bushmeat, rather than focusing on the prevention of human-to-human transmission. This has wasted communicative spaces and resources that could be used to focus on the most important form of transmission and on occasion has led to confusion of risk prevention recommendations. Banning bushmeat markets in Ebola outbreaks has backfired in the past: following the ban in Sierra Leone during the 2014-16 epidemic, people's trust of Ebola messaging decreased since many kept eating meat and people saw they did not get infected, illegal markets flourished and the coercive nature of the ban generated hostility to the response in general (Bonwitt, Dawson et al. 2018).

Emergence recommendations:

Operational

- Incorporate hunters and forest-based, indigenous communities into the epidemiological surveillance and preparedness efforts.

- Interventions should seek voluntary compliance (for example messaging on abstaining from eating bushmeat or recommendations for preparation and cooking) rather than bushmeat market bans, and should take into account the local significance and long standing experience of hunting and bushmeat consumption (Bonwitt, Dawson et al. 2018)

- In terms of information provision: a clear distinction should be made between 'dangerous' meat that can be infected with Ebola and should be avoided, and meat that can be safely consumed including pork, beef and goat. Long-term avoidance of proteins in meat can cause severe deficiencies in already nutritionally vulnerable populations (Bedford, 2018h).

- Unless the emerging epidemic has multiple cases of zoonotic spillover (rather than just one), bushmeat consumption should not be the focus of media and resource attention, certainly not more than human-to-human transmission.

Building capacity

- Development programmes, land management and private sector investment involving land-use change in forests should be encouraged to think how their activities may increase biodiversity, human-incursion into forests, and therefore spillover risks. This would also apply to governments, donors and private sector across relevant industries (mining, palm oil, wood, and so on) who have a role in shaping regulatory and policy environments.

- Research activities (e.g. modelling) aiming to understand changes in forest ecosystems and predicting future Ebola outbreaks, must work at different levels:

  - Incorporating input from different academic disciplines (as much from biological and medical sciences as well as anthropology and psychology): ecological changing dynamics of animal and human hosts, incorporating not only genetic and medical surveillance; and ecological dynamics but also transformations in social structures, land-use and human behaviour capitalising on the knowledge of local communities in forest areas and how they perceive changes in wildlife and the environment.

- Identify who is involved in hunting, butchering and trading bushmeat and seek their involvement in adapting local hygiene and consumption practices and roll-out of training programmes. These actors could in the future be eligible for Ebola vaccination.

2. Surveillance

Identification of the disease

Early detection of Ebola is crucial, as on average an undetected Ebola carrier is able to infect 1.8 additional people, doubling the number of infected every 20 days (Dhillon, Srikrishna et al. 2014). These reproductive rates and doubling times tend to be high in the initial phases of an outbreak and they eventually drop. The challenge for early detection is that initial symptoms of the disease are non-specific (high fever, muscle and joint pain) and can be confused with malaria, typhoid, yellow fever or influenza (ibid.).

Capacity to identify 'rare' diseases in remote areas is important: the existence of individual physicians in remote areas able to recognise Ebola, particularly in areas where Ebola is not considered endemic has been key to rapid response. However, early detection of 'unusual' diseases does not need to rely solely on health workers, but rather the surveillance can rely on communities and journalists to detect unusual events and deaths. In preparedness activities in 'hot-spot' areas, communities can be informed about relevant emerging infectious diseases, in order to detect unusual illnesses in their populations. In 2015 in Sierra Leone, this community capacity was harnessed by the creation of 'community event-based surveillance' (CEBS) through which community volunteers were trained to detect unusual events, 'such as the presence of two or more deaths within a single household, or the death of a traveller, and were provided with a robust reporting system' (Houlihan, Youkee et al. 2017: 139). These surveillance systems were in place *during* an outbreak, it would be interesting to see how to make them work well between outbreaks for early detection, to generate a community alert to the health system when something unusual arises. Tapping into established communication systems – which are not obviously health-related or specific - may also provide intelligence, for example, community radio death announcements may have potential in highlighting unusual events (Badenschier 2016). Social media channels including WhatsApp were also identified as useful platforms that can help identify community news and concerns (Bedford, 2018i).

Listening to how people 'speak' of Ebola – e.g. vocabulary and idioms – and other illnesses (in contrast to biomedical language) is vital, and can be revealing of important local disease categories and logics. Such understandings and the words used to describe symptoms should be incorporated into surveillance efforts, as was done in Liberia in the West African outbreak (Abramowitz, McLean et al.). This is particularly important, particularly in context were the cause of the outbreak is yet unknown. It would be useful in advance to analyse how people speak of an outbreak of a yet unknown disease that would help us identify it as possible/probable Ebola.

Local ideas of the 'source' of an outbreak may lead to public confusion about the nature of the disease. Because the majority of previous Ebola outbreaks have been rural, emerging in forest zones, there is sometimes disbelief when cases are detected in urban areas. Reluctance and/or delay in acknowledging Ebola's presence in busy cities was a factor in both the West African epidemic and in the recent Equateur outbreak in DRC. Often biomedical, social and political interpretations (e.g. witchcraft, government conspiracy) coexist and engaging in a dialogue with communities early in the outbreak helps to prevent rumours and resistance. According to de Vries, Rwemisisi et al. (2016), the speed of detection of Ebola and early presence of medical services can help to mitigate alternative explanations to the outbreak, although this would need to rely on a good foundation of trust between the community and the health system. For example, in the SUDV outbreak in Uganda in 2012, response workers did not initially seek to engage with the communities' understandings of the disease and their articulation of alternative causal explanations of witchcraft (de Vries, Rwemisisi et al. 2016).

Confirmation of Ebola infection: PCR testing is the recommended course for confirmation of cases (although ELISA detection of IgM antibodies is also possible, yet this technique is vulnerable to false positives). The logistics of confirmation is important: 'collecting samples, confirming lab results and assembling and coordinating the response team' (Dhillon, Srikrishna et al. 2014). This is not solely a technical task, equally important is people's attitudes to those outreach workers involved. In Uganda 2012, samples took a long time

to be processed because people did not want to transport outreach workers due to fear of Ebola or witchcraft (de Vries, Rwemisisi et al. 2016).

Contact tracing: Contact tracing relies on identifying those who have had contact with an infected person, and in turn the contacts of those contacts. These contacts should then be interviewed and monitored for Ebola symptoms. Contact tracing only involves people exposed to a case of Ebola (someone who may have been able to infect them). Some of these people may be incubating disease, and the purpose of contact tracing is to keep an eye on them and promptly remove the ones who become ill from the community. Contact of contacts are a useful category for vaccination as they could be potentially exposed to the disease (see below). In practice, contact tracing within communities translates into particular people singled out for interviews and perhaps having their temperature taken. If the contact if found to be symptomatic, they should be transported to an ETC and tested there. Testing the patient while they are still in the community is to be avoided, as it delays their being moved to a safer location.

People may not understand why some people receive attention and others not. For example, in Uganda, a woman who lived next door to a house in which the whole family had contracted Ebola was perceived by the community to be the 'canary in the mine' of Ebola transmission. People saw that if Ebola (as opposed to a non-natural explanation) was the cause of the disease, she should have fallen ill too; yet because she was not on the list of contacts she was not followed up on or visited, which raised some distrust and misgivings among the other community members (de Vries, Rwemisisi et al. 2016). Transparency is paramount, and response workers should explain why actions are being taken. Engaging with communities in advance, identifying influential and credible intermediaries, and listening to people's experience of the disease, the response and the emerging conflicts played an important part in mitigating resistance (Anoko 2014).

At the onset of the Ebola outbreak in West Africa, different people were identified as 'superspreaders' i.e. people whose social characteristics may mean that they are more likely to spread the disease. For example, in the initial phase of the West African Ebola outbreak, a midwife, a doctor and the funeral of a traditional healer were linked to a high number of new cases. These people had visited a large number of family members and patients, and in the case of the healer, her high status made her funeral draw crowds (Wong, Liu et al. 2015). However, this notion of 'superspreader' individuals was found to be highly stigmatising and misinterpreted the reality: rather than stereotyping individuals as 'high-risk' (Richards 2016, Richardson, Barrie et al. 2017), it was more accurate to trace 'superspreader events' (funerals, care practices, and so on) when tracking the disease (Tiffany, Dalziel et al. 2017).

Human mobility and the origin and spread of the disease: Whilst stating the obvious, country boundaries do not apply to virus or social groups, particularly in the forest belt of Africa: kinship, ethnic, inter-ethnic, political and (informal, or 'hidden') trade networks cross over administrative borders inherited from colonial times. This was the case of the Kissi, who have seamlessly moved in in the Kissidougou region that extends across Guinea, Liberia, and Sierra Leone, 'visiting community members to support their needs: attending births, marriages, and burial ceremonies.' (Wauquier, Bangura et al. 2015: para 11). The first chain of Ebola transmission of the West African outbreak emerged there, and they responded by activating their spatial and social networks: 'burying their dead, intimately supporting struggling families and patients, and seeking help from nearby traditional healers.' (ibid.) Hence, the social response to Ebola occurred within that transboundary region of Guinea, Liberia and Sierra Leone. In North Kivu, illegal trading networks (for example, timber and diamonds) cross multiple provincial and national borders and reach as far as Kenya and China. Armed groups – like the Allied Democratic Forces – in the *Grand Nord* were also found to be networked with neighbouring countries and regularly cross the Congo-Uganda border. Cross-border refugee movements and internally displaced people also move freely between provincial and country borders (Bedford, 2018f).

Paul Richards et al. called Ebola a 'disease of social intimacy' (Richards, Amara et al. 2015), in that it targets 'the social': those that meet their social responsibilities and emotional needs to care for their loved ones, it targets

healers and doctors, who are highly respected people in their communities, and targets those who properly look after the dead. This has implications in terms of the social mechanisms in which the disease emerges and spreads. On the other hand, the recommendations to address it are antisocial: family members are discouraged to touch their loved ones, or to mourn their departed and bury them according to custom. These characteristics of the disease make Ebola challenging in terms of reconciling the affected communities' public health needs with their emotional, spiritual and material needs.

Understanding the local family structures and social order and how that translates into responsibilities for care and burial is crucial to understand where a patient might be moved to, who will be responsible for their care, and if that person were to die, by whom and where this person will be buried. For example, in Sierra Leone, in Gbo Kingdom, Richards (2016) described how in marriage it is the woman who moves from her village of origin to the man's household. Unless the bridewealth is fully paid, the right and responsibility to care and bury the woman rests with her family. If she cannot be moved when ill, female family members will travel to the man's village to care for her. On the other hand, if the bridewealth is paid, the health care and burial decisions rest with the husband. Hence, in Ebola, under these circumstances, many ill women would be transported to their home villages for care and/or burial, as was the case in West Africa 2013-2015. Thus, these obligations of care and burial will depend on each local context as well as the individual circumstances of the family involved. This example highlights the importance of understanding the role that mobility plays in determining transmission patterns, and thus the response needs to be capable of mapping these mass population movements. There are positive experiences in participatory mapping of people's cross-border movements related to preparedness and surveillance for infectious disease by IOM, which would be applicable to Ebola (IOM 2018). This is useful beyond contact tracing, as it also supports epidemiological research (e.g. reconstructing why a case popped up in a village where no transmission had been going on), vaccination and risk-communication (e.g. identifying locations at risk for outbreak expansion and take proactive measures based on known social ties).

Contact tracing efforts in a conflict affected or politically unstable area: can be restricted in multiple ways. This disruption extends to all other response efforts: active case-finding, health communication, safe burials, support to local health structures, etc. We will explore the conflict-related elements in each section. In the ongoing 2018 Eastern DRC outbreak, chronic insecurity, episodes of violence and the political situation create an almost impossible backdrop to the response, who are unable to reach certain 'red zones' in Ituri and Kivu. The affected areas in Eastern Congo are occupied by around 140 armed groups. Research also highlights that local governance structures have been weakened by mass violence and killings (Bedford, 2018f,i,j). Ready-made authority mechanisms and trusted networks have been removed, which makes contact tracing more difficult. An unsecure political situation – e.g. contested, upcoming elections – mean contact tracers also battle community resistance and fears around the origin of the outbreak ('to kill opposition', 'to halt elections', etc.) (Bedford, 2018 f).

In conflict areas, substituting social groups can take the place over family. Research in North Kivu has highlighted that armed and political groups may take precedent over the family during the time of war (e.g. in particular for child soldiers, or those who have already lost many family members). This shift of family care to other forms of care when part of an armed group shapes how the disease is transmitted. Being part of these types of social groups can have an impact on a person's ability to access care – e.g. lack of amnesty – or the medical personnel that someone has access to e.g. army doctor, plant medicine. Unavailability of healthcare services is also much more common in an armed conflict or in a refugee/internally displaced setting (Bedford, 2018f). Armed groups could be important to help facilitate contact tracing efforts but may also be subjects to contact tracing themselves. One should be cautious of involving armed groups, as for contact tracing to work, tracers need to be welcome and receive honest descriptions of how contacts are faring. Historical mistrust of armed groups, the military or the police would undermine this strategy.

Surveillance recommendations:

Operational

- Find out the diversity of local social structures (including family) and associated gender, age, political and other obligations and affiliations, as it will yield information on who cares for Ebola patients, where they are cared for (or transported to); and information about where an Ebola victim will be buried and by whom (who will prepare the body). Also, map the challenges these groups have with getting access to medical care and health information.

- Transparency is paramount and response workers should explain what they are doing and why, both to those immediately affected (e.g. those interviewed and tested in contact tracing) and to the surrounding community. This is particularly important in areas where government and international agencies are systematically distrusted as a product of historical grievances. This is exacerbated in ongoing crisis areas with systematic violations of human rights or an on-going armed conflict.

- Contact tracing and communicating at a local level must incorporate how people react to their first-hand experiences (what they see of who is infected and who is not, who is interviewed and who is not), and constantly discussed with the communities.

- Ideally, response should be delegated down so response workers are from the host communities to enhance trust, so they are not perceived as 'outsiders' who might have hidden motives. This is particularly important in conflict-affected and politically unstable contexts in which distrust of 'outsiders', government and other international agencies deteriorate over time. That said, not all response workers will be trusted just because they are from a host community. Awareness of local politics and power dynamics can help pick local workers who are more likely to be trusted.

- Map patterns of population movements to trace and prepare for transmission to secondary sites, including the use of participatory methodologies. Be mindful of and ask specifically about clandestine travel and trade routes and illegal border crossings when assessing population movements.

- When responding in a conflict affected area it is important to negotiate access to the areas that are under the control of armed groups to facilitate the movement of response teams, provide information, undertake response activities including surveillance and contact tracing, and secure the safe passage of community members accessing services. It may therefore be necessary to engage non-traditional actors including armed forces and militia; members from across the political spectrum; business owners of legal and illegal businesses, always gauging how engagement then shapes (or may jeopardise) access. It is important to assess their (often conflicting) motivations and to have open, diplomatic dialogues stressing the importance of fighting the common goal of stopping Ebola in the area (Bedford, 2018f) and maintain the appearance of neutrality and non-partisanship.

- Directly engaging local associations and authorities will be critical for the success of any contact tracing activities, but the response should also be aware of relying on those in formal authority and should ensure that contact tracing works through a wide range of influencers at different levels (Bedford, 2018f).

Building capacity

- Incorporate systematically collected social science data and community level data in the preparedness phase, to incorporate into surveillance: identifying indicators (according to disease, country and population groups) that shed light on behaviours critical in predicting and responding to the next outbreak. Once you have an outbreak and know the communities affected, learning their beliefs and behaviours likely to affect disease transmission and interaction with outside disease control agencies is invaluable. Surveillance should be continuous, as the drivers and dynamics of the epidemic shift as the epidemic evolves.

- Health staff and response workers should be aware of local language of illness and categories of symptoms, challenges to accessing care, to be able to discern when Ebola arises.

- A cross-country/province/health-zone coordinated surveillance and response is often necessary as kinship, ethnic, inter-ethnic, political and trade networks in Africa often cross borders.

3. The political economy of the national and international response

The West African epidemic was a telling example of how politics can become easily embroiled with public health decisions. Evaluations of the response led to significant reforms within the WHO and the global health architecture, as well as an increase in investment in health systems of developing countries to prepare for future outbreaks.

At the onset of the West African outbreak, affected countries were not prepared to detect the disease through their national surveillance systems. For example, Guinea did not detect the virus until May 2014, when the disease had been present since December 2013. Further, WHO underestimated the risk when it carried out its assessment in May 2014. The reported cases were declining at that stage, but the infection was actually on the rise with many cases unreported (Heymann, Chen et al. 2015). The WHO did not declare a Public Health Emergency of International Concern until August 2014, and the affected countries delayed acknowledging their epidemics and declaring states of emergency. Critics of the WHO say that the delay was based on non-medical priorities such as not 'angering' African countries, as it would create significant economic losses (Kamradt-Scott 2016). These allegations are however denied by the WHO.

The political leadership of Guinea and Sierra Leone at first downplayed the outbreak (Kamradt-Scott 2016). Liberia's party politics got in the way of the response, with the Liberian president not visiting the most affected area in Monrovia, an opposition stronghold (and hence fuelling conspiracy theories of Ebola as a way of attacking the opposition). That said, the government subsequently played a role in flagging the crisis to the international community. In Sierra Leone and Guinea, the government and opposition parties (and their respective partisan media), used Ebola as a tool for political competition (Wilkinson and Leach 2015), and the Sierra Leonean president initially declined to visit affected opposition-stronghold areas. Similarly, at a local level, the relationship between politicians, chiefs and local administrators was crucial to understand the flow of power and resources, as well as to explain rumours and patterns of resistance that emerged (Wilkinson and Fairhead 2017). These suspicions arose, for example, if a chief had links to a local mining company, or whether a government minister had links with local youth groups, though in Sierra Leone there was also a common notion that response workers were profiteering from Ebola (ibid.). This highlights the need for financial accountability with communities in emergency situations more broadly. These examples also show the importance of accurate reporting in emergency situations: partisan media and 'fake news' served in Liberia to deepen political divides.

The speediness and size of an epidemic response depends directly on the funding priorities set by considerations of the Global North. Global priorities have shifted in the recent years towards Global Health Security: creating global partnerships for health surveillance for rapid response, increased authority of the WHO and the development of medical countermeasures (Hutton 2018). The International Health Regulations (2005) had committed donors to fund pandemic preparedness and response as well as provide staff resources in the case of an epidemic. However, these guidelines were not mandatory and relied on self-reporting, and WHO would in any case need to be invited by countries to intervene. In the case of Ebola in West Africa, the international response only materialised when Ebola cases started spilling over to the North, rather than at the onset of the epidemic, when the virus had spread to three countries (Moon, Sridhar et al. 2015). Further, cuts at the WHO meant a decreased number of skilled staff and lack of the financial resources necessary to mobilise effectively and quickly.

There were several months' delay for funding commitments to translate into an operational response, hampered by difficulties in transport (Moon, Sridhar et al. 2015). The bulk of the response thus arrived very late, and whilst it played a central role in stopping the epidemic, local and community responses had already turned the tide in many places (Richards 2016). Late arrival of funds could lead to confusion and mistrust: for

example, people would hear on the radio that the epidemic was abating yet would at the same time witness new ETUs being built. As a result of the lessons learnt from the response to the West African outbreak, the World Health Assembly created a WHO-managed Contingency Fund for Emergencies which would liberate funds immediately whenever a health emergency occurred. Although it does not meet its fundraising targets, the CFE was successfully mobilised for the 2018 Ebola outbreak in Equateur province in Congo (WHO 2018). Further, WHO now has a stronger mandate assigned by donors (despite its chronic underfunding) to make decisions on global health (Moon, Sridhar et al. 2015).

It is important to note that there may be differences in perspective regarding 'what constitutes an emergency', and 'who decides'. Whilst response workers may wish to rush in to deal with particular disease outbreaks, the priorities of communities may differ (for example, the economic sustainability of their livelihoods and so on), and this may cause tensions. Further, there are significant consequences in terms of reputational risk (to governments of affected countries or to aid organisations involved) when emergencies are declared, or risk-levels increased. For example, the declaration of Level 3 emergency that releases funds is politically sensitive and may highlight tensions between local and global priorities.

Institutional set-up: Including the coordination of humanitarian, national and sub-national actors. According to the UN High Level panel on Global Response to Health Crises, the initial response to the West African crisis showed a 'fragmentation of international efforts to support health systems in the developing world that lead to overlapping efforts and reporting requirements, a lack of coordination, and a significant reduction in aid effectiveness' (UN High-Level Panel on Global Response to Health Crises, 2017). In response to these initial challenges, UNMEER was set up to enhance that coordination. Indeed, UNMEER succeeded in creating a common operational platform of the response, engaging politically with the affected countries in an inclusive way and incorporating a much needed regional approach (ibid.). Yet according to the Harvard/ LHSTM review, some coordination problems persisted between UNMEER, on the ground UNOCHA and the UN emergency coordination, international NGOs and others. Lack of coordination was a problem throughout the response (Moon, Sridhar et al. 2015). There was also insufficient coordination between the three main countries affected; Guinea, Sierra Leone and Liberia (ibid.).

UN agencies and international development actors may not be perceived as impartial and politically neutral by the affected population (Bedford, 2018f). The North Kivu and Ituri outbreak (2018 – ongoing) highlights the complexity of relations between the population and the United Nations security forces. Whereas alignment between the Ebola response and UN peacekeeping mission MONUSCO (*Mission de l'Organisation des Nations unies pour la stabilisation en République démocratique du Congo*) is necessary given the security situation, the union is complicated. To gain community confidence and trust, responders were advised to use clear visual markers to be able to quickly and easily distinguish personnel and vehicles associated with the Ebola response. It was also highlighted that it was important to give thought to how uniforms or other markers that identify Ebola responders could be misused by armed groups - who can try to access army uniforms and other markers to conceal their identity and to appear trustworthy (Bedford, 2018f).

There is a need to understand the health response as embedded in a particular politics, for example in Sierra Leone during the West Africa Ebola Outbreak (2014-2016), where the situation is one of 'acute external dependency, patron–client politics, endemic corruption and a weak state unable to provide basic services and protections to its population' (Anderson and Beresford 2016: 469). Also, where health systems funded with a high volume of foreign resources encourages 'rent-seeking among politicians and local health professionals' is particularly acute in a sector that attracts such high volumes of external resources (ibid.). This fuelled accusations of the State 'eating Ebola money' (Shepler 2017). For example, in Equateur province in Congo, there is a tension between customary and civil administration authorities (Samndong 2016). The North Kivu and Ituri outbreak (2018-ongoing) also highlights how politics can play a serious and influential role in the outbreak. Some local authorities have politicised Ebola and there are concerns about how the outbreak may be used for political gain during the upcoming election campaign as well as how it may effect the ability of people to vote.

Given Eastern DRC is an opposition stronghold, and given that high levels of insecurity are perpetuated, it is no surprise that the virus is believed to be 'a new weapon of the war'. There is a widespread perception that the same actors who were thought to be behind the kidnappings and killings, are now behind the current Ebola outbreak (Bedford 2018f). It should not always be assumed that UN missions and international response actors are perceived as welcome, supportive or positive by communities. UN forces have become embroiled into the conflict and, as such, are not always perceived as being politically neutral in the eyes of the population.

Lastly, ethnic cleavages may be crucial to understand voice, representation and involvement in (and resistance to) the response. Party politics can be drawn along ethnic lines, and, depending on the historical and political context, the response could risk being seen as one ethnic group taking advantage of the situation. This was the case in Guinea, where the 2013-2015 Ebola outbreak arose in the forest region, a traditionally marginalised region subject to hostile colonial and post-colonial policies, and where the government had implemented controversial land and mining deals that were perceived as corrupt and exploitative to workers. Indigenous forest dwellers interpreted the Ebola response as a further attack on them (Wilkinson and Fairhead 2017). Similarly, in the recent outbreak in Equateur province in Congo, 2018, many ethnic communities coexist, including the Mongo and the Twa. The Twa are systematically marginalised, their interests are rarely incorporated into customary or administrative arrangements (Samndong 2016). They are vulnerable to accusations of being Ebola-bearers. (Bedford 2018) and are more likely to be discriminated against in health clinics (ibid.). It is however, important not to assume ethnic cleavages as a driving force, in Sierra Leone, for example, economic (not inter-ethnic) concerns dominated, with concerns by the poor about Ebola money being funnelled to elites (Wilkinson and Fairhead 2017).

Politicisation of the Ebola response: political and armed conflict can also have a real and negative impact on the Ebola response. In any conflict affected area, there is a significant risk that the outbreak and the response will become politicised and that factions at both the national and provincial levels may use it according to their own agendas. As Bedford (2018f) concluded, people in North-Kivu believe that certain political and influential local authorities potentially benefit from prolonging the outbreak, and there is some evidence that misinformation is being deliberately circulated for political gain. As a community leader in Beni confirmed, 'because this is political season, politicians will manipulate the information about Ebola'. As was mentioned above, Ebola is also viewed as the latest 'weapon of war', in a civil war that has been in North Kivu for the last 14 years. Promoting misinformation for political and violent ends is commonplace in the *Grand Nord* and as such communities in North Kivu are vulnerable to misinformation and political manipulation of Ebola. The response itself can be a target of misinformation, for example narratives of international agencies were stealing natural resources (the affected areas lay on important trade arteries of illegal and very profitable trade routes of diamond gems and precious timber) are commonplace, or that the response was taking a side in the conflict. These perceptions have created anger towards the response and been part of the reason that healthcare workers and other response agents working in North Kivu have been received with suspicion and even violence.

The risks of politicisation of an outbreak and the response must not be underestimated and measures should be anticipated to counter misinformation. It is imperative that the political neutrality of the Ebola response is emphasised consistently at all levels. High levels of distrust between different sections of the population can lead to scepticism about both the virus and the response. Scepticism and distrust contribute to on-going practices that heighten the risk of transmission, issues around vaccination, widespread community dissatisfaction, and incidents of escalating violence against response teams (Bedford, 2018f).

National and international response recommendations:

Operational

- Conduct a (rapid) *political economy* analysis:

    (i)   Understand the power dynamics and diverging interests shaping the global response (donor, WHO and Ebola affected countries) at that particular time.

    (ii) Gauge the relationship between different humanitarian actors and their dynamics of cooperation and competition; and

    (iii) Analyse the national and local political context and the legacies of history e.g. relationship between customary authorities and political authorities; ethnic, social and economic cleavages, and so on.

- Analyses should be conducted in the preparedness phase, at the beginning of an outbreak and as part of monitoring activities during an outbreak. These dynamics will determine the capacities for surveillance and response of both the national health systems, but also the directions taken by the humanitarian actors.

- When operating in a complex, conflict affected or political context it is important for the response to be perceived as politically neutral. Their neutrality needs to be reinforced by visual markers which need to be clearly distinguishable from other political forces in an area.

- Visual markers that identify Ebola responders may also be misappropriated (for example, by armed groups) and a mechanism for safeguarding access to such markers should be established.

- When it is needed to engage with leaders of armed forces, army officials or other political actors it important to be perceived neutral whilst operating with a high level of diplomacy and sensitivity. As per the suggestion above, interactions need to be ingrained in an excellent local understanding of the conflict, the political situation and local partnerships with neutral actors are necessary to navigate political challenges.

4. Transmission

Biomedical to non-natural explanations about how Ebola is transmitted co-exist within affected communities. These beliefs on the causality of disease and how to address it are not static: they adapt to material circumstances, changing environments and the learning process of communities and responders. In Liberia, when confronted with 'accelerated mortality', communities were more likely to incorporate health information, provided they 'acquired and validated information through local networks'. (Abramowitz, McKune et al. 2017: 64). This capacity to learn and adapt practice was present even before the surge of humanitarian health messaging, as communities shifted care and burial practices as a result of their confrontation with the disease (Richards 2016). The capacity of communities to learn should be harnessed. There are also pre-existing cultural systems that are adapted to outbreak control (see below). Communities can and have played a significant role in containing the disease when two-way communication is opened with response workers and where epidemiologists provide timely and relevant advice to local agents and vice versa. The resulting dialogue makes 'communities think like epidemiologists, and epidemiologists ...think like communities' (Richards 2016: 129)

Biomedical explanation

Ebola Virus Disease is transmitted from human-to-human by close contact with a patient. It requires direct contact of breaks in the skin or mucous membranes with infected blood, tissue or body fluids (sweat, vomit, diarrhoea), through syringes or chirurgic equipment or something bearing a patient's infectious secretions e.g. dirty bed linens. The virus stays active in objects contaminated with blood and body fluids of an infected person. Hence, infection often occurs between patients and their carers or from patients to health workers.

In the West African epidemic, more than 800 health workers were infected and more than 500 died (Currie, Grenfell et al. 2016). Male survivors can have viable Ebola virus in their semen for over a year, although it is a rare occurrence (Sissoko, Duraffour et al. 2017).

The incubation period of Ebola can go up to 21 days (hence, this is the quarantine period). The disease then takes approximately 7-10 days to begin to resolve or to cause death, the first few days is the 'dry phase', in which the patients are less contagious and their symptoms are similar to malaria (fever, malaise, and body/joint aches), and the next 3 days is the 'wet phase', in which there are in addition gastrointestinal symptoms and profound weakness, as well as haemorrhagic signs in some patients. In this latter phase virus is present in all secretions and patients should only be moved with protective gear and Ebola-prepared ambulance transport (Richards 2016). That said, Ebola-suspected patients (even in the dry phase) should be transported with the same care.

Because the disease transmission is through close contact, it is the practices that involve close contact that carry the greatest risk of transmission: (i) caring for a person who is ill at home without the necessary resources and protection (and without a way of disposing of toxic waste); (ii) physically transporting a person when they are ill (e.g. carrying them to a health centre), (iii) preparing a body for burial (e.g. washing and dressing it) when then virus load is highest. Thus, the cases cluster around households and families and around those in touch with health care workers. Were Ebola to emerge in different contexts, there could potentially be other practices that involve close contact and hence should be incorporated into the concerns of the response.

Alternative explanations of Ebola and its mode of transmission

Whilst biomedical explanations are accepted by people living in areas where Ebola is endemic, there may be other explanations of the disease. Some ailments will be considered natural, e.g. a common cold or a temporary headache, whilst other ailments (or the persistence of natural ailments) will be understood to have non-natural causes. These non-natural causes attributed to disease range very widely, depending on religion, ethnicity and other socio-cultural and political backgrounds. For example, in the recent Ebola outbreak in Equateur province in 2018, the following explanations were gathered in the literature from the region prior to the outbreak (Bedford 2018):

- Non-compliance to social rules (e.g. related to marriage, property, authority, food taboos, rites, theft and prohibitions) by the person or their family

- Interpersonal conflict (e.g. jealousy, resentment, about resources and land)

- Disrespect of deceased parents and ancestors

- A particular relationship between the patient and spirits. In Bantu tradition, if a spirit takes offence in something done by a living person or community, he may cause illness or misfortune to those persons.

- Divine will

- Witchcraft and sorcery, ideas of which may be encouraged by Christian churches (primarily Pentecostal churches and apocalyptic movements) in their portrayal of the world as Good vs. Evil

In the Equateur outbreak, the most frequent non-biomedical explanations were witchcraft and interpersonal conflict around land and resources.

Every context will have a nuanced understanding of these causes: 'witchcraft' means different things in different contexts, and its implications for health-seeking, and treatment vary significantly. For example, in the Ebola outbreak in Congo in 2003, in Kelle Mbomo (Congo-Brazzaville), one of the salient explanations of the initial cases of Ebola was sorcery (*ekundulezanga*), in which the sorcerer sends spiritual objects into victims, in response to a person or a household's accumulation, lack of sharing, or conflict within the family. The way to address this is for a healer to identify the sorcerer and to extract that spiritual substance (Hewlett and Hewlett 2008). This extraction could go in parallel with seeking help through prayer, and does not preclude

seeking biomedical treatment or complying with quarantine guidelines that resonate with cultural responses to epidemic. (ibid.).

The example above shows that articulating an alternative disease framework may not necessarily mean that it diverges with the goals of the biomedical response. For example, Ebola was explained in the 2012 Ebola outbreak in Uganda by some as *amayembe* witchcraft, yet even under this framework, there is still prompt treatment seeking, and incorporate 'isolation and social control of those who were most likely to be carriers of the disease, because they were also, to an extent, the ones suspected of using the *amayembe*.' (de Vries, Rwemisisi et al. 2016).

Other explanations are 'conspirational' rumours (e.g. from Isoro 2012, Bas-Uele 2017) suggesting that Ebola was imported by foreigners. There has been a high level of distrust in biomedical health services, international 'white' response workers and non-local responders (e.g. from Kinshasa and other areas) (Bedford 2018). Outbreak response agencies may unwittingly play into underlying beliefs. For example, during the Yambio outbreak (2004) MSF, in hiring local nurses and paying them a fair wage (as determined by MSF pay scale for local workers), led some locals to believe that these nurses were in league with Mami Wata (a creature that exchanges power for the lives of family members), as their newfound wealth was considered suspicious.

In North Kivu, people explained the sudden outbreak in the area as a way for people to gain personal or political influence. Explanations of the onset of the epidemic included: 'to delay elections' or 'a way for Kabila to get more money' (Bedford, 2018i; Gercama - personal communication). A human rights leader in Beni territory also asserted that some of the 'rumours' that bodies are missing from graves may be a result of political attempts to manipulate the narrative around Ebola: 'The population gets instrumentalised by certain political figures, such as Mbindule. He held a political meeting, called the population, and accused ministers of Ebola. He said that the vaccine was to exterminate the population' (Bedford, 2018i).

Rural vs urban spread: in the West African outbreak, there was initial concern regarding spread of the disease in urban areas and slums. For example, in Monrovia, due to close proximity of households. However, the spread was still through care provision, and Monrovia's spectacular explosion of cases more likely happened because of how care was delivered in health structures, especially hospitals. The transport of patients in taxis may have also played a role in the disease crossing between social networks. Population density itself most likely did not play much of a role (and for similar reasons Ebola did not spread much in Conakry). Further, many urban communities were able to organise community care centres, case control and quarantining as effectively as in the rural areas; and once set in motion the response was swifter in urban areas, meaning safe holding and care facilities were quickly put in place (Richards 2016). As above, it is important to highlight here the importance of tracking populations' movements and transmission routes in and out of urban centres and into rural areas, and to ascertain if and how certain rural communities may have close ties with certain neighbourhoods where families have gone in search or employment and where there is regular movement to and fro. This has to be done in parallel to tracking population movement across borders, contrasting them with the results of epidemiological surveys over time.

Transmission recommendations:

Operational

- At the onset of an intervention and in preparedness activities: conduct an analysis of the local understanding of infection, contamination, disease, death and models of causality and fears around infection.

- Employ community engagement methodologies which give communities a voice, and a chance to be listened to. Harness two-way channels of communication methods that people already use to set up platforms between the response and communities discussing beliefs and prevention measures, acknowledging that these are fluid and change over time.

- Identify everyday practices that involve close contact between sick people and others and the meanings and social goals attached to these practices: patient care, body preparation for burial, and others.

- Identify what are the different causal explanations for Ebola illness and transmission in each context. In each cultural/political model of disease (e.g. 'traditional' witchcraft, Christian notion of witchcraft, biomedical, spirit, etc.) understanding (i) how the disease is identified through signs and symptoms, (ii) the cause, (iii) transmission (iv) risk groups, (v) pathophysiology (how it kills), (vi) treatment, (v) prognosis and (vi) prevention

- Identify potential crossovers between alternative explanations of transmission and public health objectives (e.g. community-based quarantining and movement control) for cooperation.

- Public health campaigns do not need to refute alternative explanations but rather work with or in parallel to them, managing the social consequences (e.g. stigma or marginalisation) that may arise.

- Identify who the key people are entrusted with identifying and healing Ebola (e.g. pastors, healers), and give training on Ebola epidemiology, provide protective equipment and encourage referrals to Ebola-prepared care centres.

- Identify at the same time those people who are spreading misinformation and fear about the origins of the Ebola virus or the response. Identifying these dangerous counter narratives and educating the affected population on 'false news' channels are important steps towards solving resistance against the response.

Building capacity

- Training for healthcare workers on Ebola and appropriate biosecurity should take place at the earliest possibility during an outbreak and should include practical recommendations given the existing resources.

- Engage with communities and other social groups in a dialogue to promote mutual learning: response workers learning about the local context and communities learning about the determinants of disease transmission.

5. Vulnerability

Vulnerability to the disease

Likelihood of infection or death involves separate dynamics. Among others, vulnerability to infection is shaped by gender, age, profession and social position as these determine responsibilities in the care of the sick and burial practices. We explore these dimensions below.

Gendered vulnerability: Biologically, women and men are equally likely to get Ebola, but gendered social norms and practices may make men or women more vulnerable to infection at different stages. Gender norms determine who are the caregivers and thus will have close contact with ill people, and they determine access to health services. In the West African context, women are the primary caregivers 'in their homes, communities and health facilities' (Menéndez, Lucas et al. 2015: e130), and thus they will be more vulnerable to infection by virtue of coming into contact with symptomatic patients. There will be local nuances to this trend, for example, in the example of the Gbo in Sierra Leone detailed above, adult men are cared for by their wives and eldest son, adult women by the eldest daughter. In terms of burial practices, it also varies according to culture and religion. For example, the 2000-2001 Ebola outbreak in Gulu, Uganda, affected mostly the Acholi people. Amongst the Acholi, it is customary for women to wash the bodies[3], either the father's sister of the deceased, or if the father did not have a sister, then another older woman in the father's family. Thus, the death rates amongst women were much higher in this outbreak. In Sierra Leone, however, men prepare men's bodies and women prepare women's bodies; whereas in Muslim households women wash all bodies (Richards 2016). Transport of the sick and dead is also gendered, in Sierra Leone for example; hammock carriers were mostly young men, who carried the ill in remote areas in a hammock until they reached a road. It is thus important to

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[3] Please note that for the Acholi, when *gemo* (epidemic) is declared, the body is not washed or touched before burial.

find out what roles men and women perform: from care, body dressing and washing, as well as transporting sick or dead people.

Gender vulnerability goes beyond the likelihood of infection: pregnant women coming from Ebola affected communities are likely to receive discrimination in attending maternal healthcare (Menéndez, Lucas et al. 2015). Otherwise, that maternal healthcare service may not exist anymore because of Ebola deaths. Further, in some contexts women depend on their husband's permission to seek treatment, and hence might not be able to go to a clinic. Lastly, women are less likely to have control over their sexual choices, and may be exposed to the virus through the semen of male Ebola survivors (Menéndez, Lucas et al. 2015). This is particularly important to consider in conflict affected areas with high rates of sexual violence. Similarly, the burden of losing a spouse is also gendered, women or men might have different levels of difficulty when they are left to care for the household, or are left economically vulnerable. Research conducted in Equateur province in DRC (Alcanya-Stevens, 2018) highlights that *Mongo* women who mourn over their spouse are often not able to leave their houses during this period, which caused them to miss potentially life-saving Ebola vaccine opportunities.

Age: babies are most at risk, but children, from when they are toddlers up to the age when they take adult responsibilities of care (around 15) are less at risk, as they are often separated by the family from the sick person (Hewlett and Hewlett 2008). During the West African outbreak adults, who were involved in caring, preparing and burying the bodies were more at risk (3-4 times more than children), particularly so the eldest: people over 45 were 4-5 times more likely than children to be infected (WHO Ebola Response Team 2015). In North Kivu and Ituri, WHO reports that children account for 60% of the total cases and further research is needed to showcase why this large number is affected by the virus (Branswell, 2018). There is speculation that these children were taken to healers for malaria treatment, and these healers were also seeing Ebola patients. As mentioned above, in some contexts young men are assigned the role of carrying sick people unable to walk (e.g. on stretchers). They may also dig graves and carry corpses, increasing their risk of infection. In North Kivu young people are also at risk of abduction (from or to Ebola affected areas) and recruitment as child soldiers – areas which the response cannot access which makes that they are more at risk of infection (Bedford, 2018f).

Remoteness: remoteness may play a role in both putting people in touch with hosts and infected primates (although bats are increasingly finding space in urban areas), but also creates difficulty in containing the epidemic when moving from A to B. In affected rural areas of West Africa and Congo some villages are only accessible by motorbike or on foot, making the movement of infected people more difficult, and hence in some cases remoteness has stopped transmission (as happened for example in Likati). That said, remoteness also means that if Ebola does reach a community, then access to treatment will be much more difficult. Similarly, remoteness shapes the trust of outsiders. The distance to the nearest health centre (and the related cost of travel) are determinants of vulnerability to death from the disease (Stanturf, Goodrick et al. 2015).

Health staff: as mentioned above, many health workers (formal and informal) are often infected in Ebola outbreaks, particularly in the early phases of the outbreak, in which care is provided before receiving the adequate protective equipment and training; and before the system for transporting, holding and quarantining Ebola patients is set up (Stanturf, Goodrick et al. 2015). Traditional healers and pastors can be equally vulnerable to infection, as they may be the first port of call when someone falls ill with Ebola. As shall be shown in the section on communication, health workers and healers are often stigmatised. Similarly, other professions that involve close contact with infected people or bodies will have higher risk of infection, e.g. working in transport, burial workers, and so on.

People in close contact with host animals and primates: hunters and people whose livelihoods rely on forest resources may be more likely to come into close contact with a fruit bat carrying Ebola virus or an infected primate. During the Ebola outbreak in Equateur, it became clear that Twa communities were providing the *Mongo* majority population with hunted bushmeat that did not only make them more vulnerable to infection, but also to being blamed for the Ebola outbreak. As mentioned above, bushmeat messaging should be discouraged as it provides fuel for stigmatisation and is relatively unimportant once the outbreak has emerged.

Ebola victims, survivors and Ebola orphans: are likely to be stigmatised by their own communities. Stigmatisation can consist of shunning and isolation, ill-treatment, the rejection of treatment and political or economic exclusion (ERAP 2014). Due to fear of stigma, on occasions people may hide their illness or that of their family members (Hewlett and Hewlett 2008). In certain context, even being identified as a contact in contact tracing can be met with stigma amongst the community (ibid.). One way to address stigma could involve the health system reassuring the community of a survivors' health status to prove they are no longer contagious[4]. For example, ERAP proposed a step-by-step reintegration of the survivor into the community linked to a 'social contract that tied targeted support to adherence to infection control practices' (ERAP 2014: 1).

Those living in occupied territories and members of armed groups: citizens living in occupied territories or in areas where armed and rebel groups are active may be particularly vulnerable to the Ebola virus as response actors may not be able to access the areas they operate due to security and safety regulations. This includes members of armed groups and militia who might be hesitant to visit healthcare centres, as they might fear arrest, or their lives having to cross the territory of another group (Bedford, 2018f).

Refugees and IDPs: and particularly those who live in informal tented settlements, are particularly vulnerable to the Ebola virus because of their (cross border) movements and/or the lack of healthcare services in their settlements (Bedford, 2018f).

Vulnerability to the consequences of the disease

As mentioned in the previous section, non-natural explanations of the disease may dominate. In different Central and West African contexts, the explanation of witchcraft or sorcery as the source of Ebola may mean particular people are targeted as witches or sorcerers, and may be subject to ostracism or violence. Sorcery as an explanation of illness or death is more prevalent when the status of the ill person is high (HEART, 2014). The particular context and cultural understandings of sorcery will determine who is more vulnerable to accusations of witchcraft in an Ebola epidemic. In the case of Congo, those accused of witchcraft or sorcery in previous outbreaks have been (i) people or families who might be perceived to have ill-will or jealousy towards the patient or their family, (ii) family members who might be accused of benefiting from the person's death or illness, for example widows or mothers of the deceased[5], or (iii) particularly marginalised people or social groups that are seen as outsiders or in touch with non-natural forces, for example street children or indigenous groups such as the Twa in Equateur (de Vries, Rwemisisi et al. 2016, Duda, Alcayna-Stevens et al. 2018). Stigma can also apply to whole populations as well as individuals: 'community X has Ebola' meaning people avoid the area and people from that community, this often has economic consequences.

Fear of the disease can generate xenophobic and anti-immigration sentiments and the scapegoating of whole communities (Kim, Sherman et al. 2016). For example, African immigrants in the US and Canada suffered stigma during the 2014-16 pandemic (Adeyanju and Oriola 2010, Cincinnati 2015).

The response must identify these vulnerable groups at an early stage and community engagement and communications should aim to protect them.

Vulnerability to the response

People who participate in bushmeat hunting and trading may be affected by trade bans and may be at risk of being perceived as the source of the disease. In Equateur, DRC 2018, it is the *peuples autochtone* – also called the Twa or derogatorily, pygmies – who make money from selling hunted bushmeat and who ended up being blamed for the start of the Ebola outbreak (Alcayna-Stevens 2018). That said, populations have been quick to realise that the risk of infection via bushmeat was negligible vis-à-vis human-to-human transmission (Richards 2016).

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[4] This has become more difficult with the knowledge of persistence of the virus in semen. Despite this being a rare occurrence, this possibility may generate distrust in communities into which survivors are being reintegrated.

[5] Note that witchcraft accusations are gendered as well, in some contexts women are more likely to be accused of witches whereas men more likely to be 'bewitched', as in the case of Lassa Fever in Sierra Leone.

Trade and movement bans have different impacts on different communities, in terms of missed educational or economic opportunities and unsustainable coping strategies (e.g. selling assets). For example, in the case of West Point quarter in Liberia, the lock-down on movement meant that people who sold smoked fish to other parts of the city could not do so, damaging livelihoods and food supplies thus increasing risk of hunger. This added to the mistrust of the government that eventually led to protests. In the case of children, school closures meant children missed school, for example in Sierra Leone schools were closed for eight months, so children missed a whole academic year. Teenage pregnancies also rose during the crisis in Sierra Leone (Denney, Gordon et al. 2015). In North-Kivu, the start of the new school year in September brought anxieties relating to the spread of Ebola. Schools are still closed out of fear for infection, and – at the point of publication – the teacher's union has called for all schoolchildren and teachers to be vaccinated prior to the start of the school year (Bedford, 2018h).

Some populations may be left out of the response. For example, a particular social group may be stigmatised and will have difficulties in accessing health care (Benjamin, Jacques et al. 2015), and discrimination may mean that they might not seek biomedical health care even when it is accessible (ibid.). Remoteness combined with low incomes may mean, as occurred in the West African outbreak, that people seek care at home rather than specialised care further afield (Richards 2016). Accessing care was also particularly challenging for the indigenous Twa communities in Equateur, DRC, who had traditionally been discriminated by the Bantu healthcare workers (Alcanya-Stevens 2018). The infection prevention control measures can also limit access to general health care. For example, in Liberia, the heightened measures in hospitals included one person per bed and minimum distance between beds. For this reason, the total number of beds available decreased and pregnant women were turned away from 'full facilities' (Jones, Ho et al. 2018).

Lack of political voice, may mean that a particular social group is not able to participate in decision-making at a local level, and hence when strategizing is made by response workers with the 'community', these groups may not be heard and their needs ignored (Benjamin, Jacques et al. 2015, Samndong 2016). In Liberia in 2014-16, traditional society leaders (the Poro and Sande leaders) were not initially considered when seeking alliances in the response (Pellecchia, Crestani et al. 2015). This shows how a gap may exist between who the response agencies know and who may be influential. Similarly, there may be inequalities in the access to information, and some populations (either due to income or levels of education) may be less aware of the Ebola helpline or of the content of prevention messages (Sastry and Dutta 2017). While we can identify broad groups in advance e.g. age, gender etc., there will be new and intersecting forms of vulnerability which emerge in that particular context and in that particular Ebola outbreak, which would need to be determined as the epidemic plays out, for example with rapid assessments (Napier 2014).

Vulnerability recommendations:

Operational

- Identify the gendered nature and age distribution of practices which involve close contact e.g. care of the sick and body preparation for burial. Direct engagement to the relevant people and through their trusted sources (e.g. women's groups in Equateur province in Congo)

- The response must identify vulnerable groups who are at risk of harm (widows, street children, marginalised social groups, etc.) at an early stage and community engagement and communications should strive to protect them.

- Identify through a rapid assessment, working with key influential and trustworthy people, who is left out from the response (at a local/community level as well as national/international level) due to the particular dynamics of vulnerability of the context in that particular outbreak (Napier 2014).

Building capacity

- Ensure resources directed to Ebola do not undermine other key health needs. This is a massive challenge as it involves a lot of resources and working at different levels. For example, in pregnancy and maternal health care, and ensure that these services are trained to deal with Ebola, and that they do not stigmatise mothers coming from Ebola affected communities.

- Training for formal and informal community health workers on Ebola biosecurity and other close contact diseases, with practical recommendations given the existing hygiene and protective equipment.

6. Mental health and psychosocial considerations

Because of its presentation and transmission, Ebola is a disease that cultivates fear, anger and despair and it can deeply impact the wider social fabric. Activities most likely to transmit Ebola are often those which are deeply social and psychologically meaningful, such as caring for the sick, or washing the corpses of loved ones before burial. As such, elevated levels of distress and disorder are to be expected, and an effective psychosocial response is critical (Bedford, 2018j).

Ebola-affected countries may also have weak formal mental health systems and support infrastructure. In the DRC outbreaks in 2018, whilst there was no comprehensive needs assessment of the mental health needs of Ebola affected communities, it was clear that formal mental health structures are limited and do not match the needs of the population (Bedford, 2018j).

Local coping structures and mechanisms exist and are significant, even if they do not fully satisfy the need for mental health services or other important interventions for individuals identified with moderate to severe symptoms of mental disorders. In DRC for example, to reinforce wellbeing, people turn to economic survival strategies, religious leaders and institutions, traditional healers and family members, and collective assets that promote wellbeing include music and dance. In dealing with decades of insecurity and protracted conflict with limited support from the under-resourced formal mental health and psychosocial support systems, Congolese communities have also developed various ways of coping with distress including *débrouillardise or auto-prise en charge* (fending for oneself). It should also be noted that although the psychosocial effects of violence in DRC are very real, violence has, to some degree, become normalised and is a common recourse action when frustrations become too great (Bedford 2018j).

Social networks can be entry points to strengthen mental health and psychosocial support care. In the relative absence of formal mental health structures in North Kivu, DRC, sources of psychosocial support were evident at family and community levels, particularly through church networks as mental health and psychosocial issues are often seen through a spiritual lens. Local actors including trusted and respected community leaders, traditional healers and pastors (some of whom have been trained in psychosocial support skills by the Bethesda Counselling Centre) all serve as frontline providers offering psychosocial support to their communities. Prior to the 2000 Ebola outbreak in Gulu, Uganda, the country had a significant problem with HIV/AIDS in the pre-antiretroviral era, and many families had loved ones dying at home. Many grief counsellors were trained at the time to deal with this, and they became a community mental health resource during the Ebola outbreak. Pastors and other religious leaders can also play a role in providing spiritual support to patients at ETCs and their family members, and can provide advice and support regarding burial practices and ceremonies that are both safe and meaningful to communities (Bedford 2018j).

Across Ebola affected contexts, it is important to be mindful of the terminology used for mental health and psychosocial issues. In North Kivu, for example, even if words 'trauma' and 'psychosocial' are used locally, in both English and French, they are mainly used in relation to NGO programming. In the local language Kinande (used in Butembo, one of the affected communities), *kironda echomomuthima* is used to describe psychological trauma (derived from *kironda* meaning 'wound' and *muthima* meaning 'heart'). The term is

used variably amongst practitioners and it is unclear whether people use it to refer to specific symptoms or a syndrome. It should also be noted that global MHPSS good practice cautions against the overuse of and singular attention to 'trauma' (Bedford 2018j).

Another lesson learned from North Kivu is that the response needs to be mindful of survival and people's needs outside of the Ebola outbreak. Communities in Eastern Congo perceive that their ongoing needs have been largely neglected by both the government and the international community and have expressed frustration that attention is now focused on North Kivu 'just' because of the current Ebola outbreak. It is important to address and reconcile these perceptions and ensure we listen and respond to people's needs in order to prevent further suspicion, mistrust and resentment (Bedford 2018j).

Mental health and psychosocial recommendations:

Operational

- ETCs should include trained MHPSS staff.

- Mental health and psychosocial support should be a core component of any public health response to Ebola. Understanding and addressing mental health and psychosocial issues is key to stopping transmission of the disease. Specific technical expertise and dedicated resources are required to integrate MHPSS into public health assessments at the facility and community levels and into preparation, response and recovery plans in accordance with the MHPSS guidelines of the global Inter-Agency Standing Committee (IASC, 2007; IASC, 2008; IASC, 2015). This includes the integration of MHPSS approaches and activities with community outreach, case identification and contact tracing as well as with activities at ETCs and health facilities.

- It is important to map existing local MHPSS expertise and structures as a number of private, governmental and NGO programmes and services will already be active in some capacity in an area. Existing services could provide further psychosocial support and mental health care in the context of Ebola. Local structures form the fabric of community-based care and must not be overlooked or undermined but rather engaged in partnership as contextually-appropriate channels to provide, as part of a multi-level system of care.

- The expression of distress and disorder differs across contexts, and this can govern which interventions are effective, therefore this needs to be carefully understood by those wishing to intervene.The socio-cultural aspects of mental health, psychosocial wellbeing and care must be carefully considered. Broadening the lens of interventions to address social networks (household, family and community relationships) rather than just addressing individual needs is important.

- Provide frontline personnel with access to sources of psychosocial support. This must be of equal priority with ensuring their physical safety through adequate knowledge and equipment.

Building capacity

- Train all frontline workers (including volunteers, health workers, burial team members, MHPSS providers, community leaders, teachers, pastors and other religious personnel) on essential psychosocial care principles and psychological first aid for Ebola outbreaks.

- Key psychosocial principles including hope, safety, calm, social connectedness and self- and community-efficacy should be embedded across every intervention (Hobfoll et al., 2007).

- Within the structure of the Ebola response, MHPSS should be a stand-alone technical speciality, but also cut across all response pillars. Each pillar should have clear guidance as to how MHPSS is included.

- To do so effectively, clear inter-sectoral coordination mechanisms and entry points for MHPSS technical expertise must be agreed at global, national and local levels. This will enhance the protective qualities, and reduce the potential risks, of humanitarian interventions. A key area in which psychosocial expertise is required is to ensure that burials are not only safe but also dignified.

7. Prevention measures

Non-pharmaceutical measures

Communities have local capacities to contain Ebola epidemics and the ability to learn with the response. Previous Ebola outbreaks have shown communities' capacity to modify burial practices, organise movement control and quarantines, and manage community Ebola care centres. Yet communities are often not trusted by the response to contain an outbreak: there needs to be a strong shift towards a delegation of responsibilities to affected communities and a shift towards trust. This can be backed by social science research gathering context-specific lessons learnt on what worked and how communities managed to stop the spread of the epidemic.

Communities not only have the capacity to learn and adapt to new circumstances, but also, in many African cultures, communities have longstanding adaptations to epidemic illnesses as qualitatively different to 'normal times'. This is what Hewlett and Hewlett call 'cultural models of epidemic illnesses'. They use the example of the Acholi in Uganda (affected by an Ebola outbreak in 2000-2001) to show how they understood epidemics as *gemo*, a bad spirit that comes suddenly and rapidly affects many people. *Gemo* arises when the *jok* spirits (which play a role similar to that of the elders of the community) have not been respected (and sometimes for no reason at all). *Gemo* is transmitted by the wind. Proximity to someone with *gemo* means *gemo* is more likely to 'catch you': close contact, infant nursing and sexual intercourse transmits *gemo*. When *gemo* is declared in a community, there is a protocol that resonates with public health protocols: *gemo* patients are isolated (for the space of a moon cycle), survivors are put in charge of feeding them, households with *gemo* are marked and villages put up posts up at the entrance to notify visitors, people limit their movements, food brought in by outsiders is banned, there can be no contact between ill people and pregnant women and children, and other prohibitions to eat particular foods or dance are put in place. Burial practices are also modified: the survivor/attendant is the one to bury the body, and unlike in 'normal' times, the body is not washed and is put into the grave (in the edge of the village) with long sticks rather than by hand (Hewlett and Amola 2003, Hewlett and Hewlett 2008). Note that these are practices of social sequestration, quarantine and burial practices that are part of the biomedical epidemic response to Ebola. Similarly, when addressing *gemo*, these communities strove to create 'harmony in the household' with 'no harsh words or conflicts within the family' (Hewlett 2016). This adds an extra psychosocial dimension, addressing fear, anger and stigma (Moran 2017), which is a crucial aspect often ignored or overlooked in formal Ebola biomedical response.

Hewlett and Hewlett saw similar cultural models of epidemic in the Mbomo epidemic in Congo, where the Ebola epidemic was understood as *opepe* (Hewlett and Hewlett 2008). The point being made here is that biomedical responses to disease can build on very relevant cultural models existing already within the populations they wish to help.

Restrictions on travel and trade, and quarantine

Contact tracing and care of the sick in isolation, and safe hygiene protocols, are the main tools against the virus. Vaccination (see below) should not be considered a silver bullet, but a complement to these conventional public health measures (Bedford 2018).

Country borders make little impact in countries affected by Ebola: economic, family, cultural, ethnic and language networks often cross boundaries. Closing a border may stop vehicle movement (and hence will have a strong impact on the economy and livelihoods) but, as in the case of the West African epidemic, the porous nature of borders (land or water) meant that boat, foot and bicycle traffic continued (Laverack and Manoncourt 2015). At a global level, restrictions on trade and travel were uncoordinated and at times incoherent (e.g. France banning flights to Sierra Leone and Liberia, but keeping the Conakry flights), delaying the response even further (Moon, Sridhar et al. 2015), and further sparking fear both nationally and internationally.

Quarantining in the West African epidemic was at first coercive. In Liberia, it involved the military, and communities did not understand why quarantining was necessary. This coercive attitude was met with resistance and underreporting of cases. In Sierra Leone, a three-day enforced lockdown was imposed in September 2014. Many ignored the quarantine, and the government then allowed people to go to prayers, obtaining more cooperation (Laverack and Manoncourt 2015). Similarly, the closure of markets in Liberia meant people did not know where to get their food from, fuelling resistance to quarantine measures. Coercive measures are thus often ineffective, and in parallel, they create a significant disincentive for people to admit to being a contact or disclose their illness to outbreak control agencies. This causes a problem with surveillance and control: if people want to evade detection, they often can. Preliminary engagement with communities might have mitigated tensions and enabled alternative practical solutions. The goal in order for the response to work is for people to want to be honest about their health situation, and to voluntarily seek care or protection for their loved ones.

The spatial environment shapes how the disease spreads. In the Kikwit outbreak, Mobutu ordered to cut the city off completely, blocking transit in the only two roads that led to it. The isolation and the almost impenetrable forest worked to contain the spread. On the other hand, in the case of West Africa, the disease appeared in a trading town, and the road infrastructure swiftly connected the disease to the towns (Richards 2016).

Social distancing such as the closure of public spaces is difficult to implement as a prevention measure because people may not comply. This is particularly so in the case of faith gatherings. Closure of public spaces such as markets and church gatherings should not be a priority, since these are not the primary practices that shape transmission, and people find them meaningful and necessary and will likely resist. In Liberia, after September 2014, many breached quarantine to attend prayers, so in the end churches and mosques were allowed to be visited. In those cases in schools which were closed, there was anxiety about the safety of children when they reopened after the outbreak was declared finished. Special messaging to reassure parents was necessary. Voluntary social distancing should be prioritised, with faith and community leaders being engaged beforehand to discuss closure or changes in practices. There are multiple examples with faith leaders in changing practices, for example in the 2018 outbreak in Equateur, DRC, the Catholic Church stopped giving sacraments to avoid infection in the Church. In Liberia, social mobilisation officers faced the challenge of not being able to shake hands, as was customary, to greet people in the communities: thus the 'Ebola handshake' was born, which consists of touching elbows. While simple, this is illustrative of the capacity for adaptation and creativity of both response workers and communities. Similarly, the *kola* tradition in Liberia involved visitors getting a kola nut and palm wine or spirit produced from sugarcane, and often everyone would drink from the same glass. The practice was changed so each person involved would drink from different glasses, reducing the risk of transmission.

Community-managed quarantine and movement controls

Community leaders at the beginning of the epidemic saw value in prevention as a way of stopping the spread of Ebola. For example, in Sierra Leone, some chiefs suggested communities could take care of 'improved hygiene, local surveillance, self-imposed quarantine and the community management of burials' (Laverack and Manoncourt 2015). In fact, when local and religious leaders were in charge, self-imposed quarantine was crucial to control Ebola, it reduced breaches of quarantine and aided in contact tracing and identifying new cases.

Quarantining can build upon traditional practices of hospitality towards strangers in communities, as existed in West Africa before the epidemic. It was customary for people in Sierra Leone to notify the local chiefs when they were visited by a 'stranger' from outside the community, so as to ensure these both guests and hosts were treated with respect (Richards 2016). This traditional reporting mechanism was re-enforced during the civil war period to detect infiltrators (ibid.).

In response to the Ebola epidemic and in collaboration with chiefs, customary bylaws were imposed in Sierra Leone to prevent the reception of visitors, and any visitors had to be announced to and approved by the chief (Wilkinson and Fairhead 2017). In some communities, local youth joined local task forces to ensure house-to-house surveillance of movement. This system was more likely to work in villages in rural areas in which people knew each other well and movement of people was easily detectable. However, in some urban areas it worked well, for example in Freetown, in cases where there were physical barriers (the seas, a river, etc.), communities would be able to survey entrance and exits into the neighbourhoods (Wilkinson, personal communication). Community leaders in Liberia also engaged in early warning to communities, providing after-care and money to affected families, providing food for those under quarantine whilst waiting for support by the response, and working to stop riots around Ebola.

Quarantining can conflict with duties of care, and people are compelled to meet their responsibilities towards their loved ones. As will be shown in the section of home care, communities in West Africa voiced the need to deliver PPE to the communities and allow family members to care for their loved ones (Richards 2016).

Changed behaviour

Communities across the *Grand Nord* and in other areas of North Kivu (e.g. in Goma) have changed their behaviour in multiple ways to protect themselves from the current Ebola outbreak (Bedford, 2018h):

- Communities observe movement restrictions and avoid large gatherings. For example, some people have started to stay at home rather than attend church. Others reported to be highly alert and monitor who comes into their areas.

- Modifications have been made to reduce physical contact. For example, 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'. At church communion has stopped or been amended so that the congregation does not share the same cup.

- Small business owners have also adapted their behaviour: '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'.

- Frequent hand-washing is consistently observed and hand-washing stations and disinfection points have been set up.

- Food rituals have also been adapted to become safer: 'Instead of friends drinking alcohol from the same bottle, some people now bring their own glass or cup'.

Attitude towards the response

Coercive and authoritarian response strategies are more likely to backfire and produce resistance. Resistance can be expression of the social divisions left successively by colonisation, civil wars, and post-conflict development policies (Calain and Poncin 2015: 127). In the years of the West African epidemic, however, the approach of the response shifted from an initial coercive nature, to then seeking voluntary compliance and negotiation with communities.

Acceptability towards quarantining and isolation measures will depend on 'the trust of the population with the health system, intra-communal tensions, the memory of past epidemics, and armed conflict, that shapes attitudes, the intervention of the State in a repressive or inclusive way vis-à-vis civil society, the bias and position of media, etc.' (Taverne 2015). Goguen and Bolten (2017) showed that in Sierra Leone, 'the original composition of Ebola education and outreach suggested complete amnesia among its designers of the area's long history of secrecy and suspicion of outside knowledge; a history that germinated with slavery and came to fruition under a series of corrupt governments more intent on dominating local people and exploiting resources than

they were governing' (Bolten and Shepler 2017: 361). What Goguen and Bolten emphasise is that the resolution of Ebola and the resistance and compliance to social sequestration and quarantine, does not come as a product of biomedical knowledge being accepted, but rather as a result of how local politics, social divisions and the struggle for power and material gain play out: belief change and behaviour change are not necessarily connected (2017).

It is important to study the political history of an area to understand the underlying causes of community resistance, fear and anger towards the response. The complexity of the political situation, conflict and insecurity in the *Grand Nord* have been well documented and forms a dynamic backdrop to how communities are perceiving the Ebola outbreak (Bedford 2018f). Misinformation reinforces fear and scepticism that can hamper response efforts.

Pharmaceutical prevention measures: vaccination and clinical trials

A vaccine has not been available as part of an Ebola response until the one used in Equateur province in DRC in 2018. Attempts with passive immunisation with convalescent plasma have been previously unsuccessful. Vaccine trials for the vaccine rVSV-ZEBOV were run in Guinea at the end of the West African outbreak (2015). The vaccine is now being used under 'emergency use authorisation' in recent outbreaks such as Equateur province, DRC (2018) and North-Kivu (2018- ongoing).

The procedure used in Equateur province and North-Kivu has been ring vaccination: vaccinating health workers, contacts of patients and contacts of contacts. Community perceptions and understandings on why some people are vaccinated and some are not are crucial, since there are high 'risks associated with distrust, suspicion and stigmatisation.' (Bedford 2018a).

Vaccination in Africa highlights the historical problems with colonial health systems and explains much of the resistance and rumours that emerge. In the Boende outbreak in 2014, there were rumours that response workers were injecting indigenous groups with Ebola, and that response workers were 'sucking' peoples blood to sell it (Bedford 2018). In other areas of Congo, communities sometimes associated vaccination with infection and isolation. In some contexts, particular church groups 'advised congregations against immunisation (e.g. for Polio), and in previous Ebola outbreaks (e.g. Boende 2014), some churches have counselled that 'only prayer can stop the disease'. In Equateur province in DRC where the Ebola vaccine was first introduced in 2018, vaccination efforts appear to have been well accepted with a high uptake rate. However, some community members continue to express concerns that it is a lethal injection and that it will give a person Ebola (Bedford, 2018h).

Health infrastructures as much as 'culture' may limit vaccination. In Congo for example, routine immunisation is discontinued due to logistical challenges and resource limitations. There are low coverage rates of routine immunisation in Congo, and the need to maintain a cold chain is challenging. Yet evidence shows that they are managing to maintain the cold chain for Ebola vaccine delivery (Bedford 2018). In North-Kivu additional challenges related to bringing vaccines to dangerous 'red zones' have been highlighted up by the Ministry of Health and the wider response (Moran, 2018).

KAP surveys previous to the vaccine roll-out in Equateur province showed a willingness of people to receive the vaccine (Bedford 2018), and the WHO team had successfully been vaccinated many health workers, contacts of patients and contact of contacts, totalling more than 3,200 people. At the time of writing, none of the vaccinated people in Equateur province had presented the disease, and the disease has been declared over by the WHO.

As recommended by the ERAP platform for the West African epidemic: 'local populations may not be aware that many of the drugs and vaccines to be tested are first generation and not final approved products... Ebola research is being fast tracked in human populations because of the severity of the disease'. This means that tested drugs and vaccines may fail (or have undesired secondary effects), and populations should be made aware of this (ERAP 2015).

Context-sensitive and comprehensive consent procedures need to be tailor-made to fit the communication needs of affected communities. Communities in Equateur province, DRC, during the 2018 outbreak, for example, reported being unsatisfied with consent procedures with many reporting not having been able to read the information provided to explain the consent procedures. The form was written in French, a language which many in rural areas in Equateur don't read or speak. Communities also reported the importance of being able to ask questions about the working of the vaccine after the outbreak had finished.

Fears around the side effects of Ebola vaccines should be recorded and addressed. People in North Kivu report to fear infertility as a side effect of the Ebola vaccine. In Mbandaka, Equateur, for example, some mothers who were vaccinated in the early stages of the outbreak lost their baby in stillbirth or a few days after giving birth. Whether or not these women lost their babies because of the vaccine or because of other maternal health challenges is not clear. It is clear, however, that these instances have and continue to spread fear amongst affected populations in the area (Alcayna-Stevens 2018). This is context-specific, for example in North Kivu, community feedback highlights how pregnant women are asking to be vaccinated. If misinformation does not lead to refusal for the vaccine, it is still important to address fears around the long-term effects of the vaccine (ibid).

Prevention recommendations:

Operational

- Prioritise, if the context allows, community self-imposed quarantining or isolation: seek voluntary rather than coercive compliance in collaboration with trusted and influential community leaders.

- Ensure people in quarantine have food, water, disinfectant; appropriate basic equipment (bucket, drinking glass for the patients), money (including rent money for those not infected that live in a household currently under quarantine), information as well as psychosocial resources. These psychosocial resources should promote a sense of safety, hope, calmness, social connectedness, self and community efficacy (Hobfoll, Watson et al. 2007), building on the social support mechanisms that emerges in crises.

- Conventional public health measures of quarantining, movement control and contact tracing, and biosecure facilities for symptomatic treatment of Ebola are the main routes to contain Ebola: vaccination should be in addition to these.

- When vaccinating, initiate community mobilisation before the start of the campaign /trial to avoid negative associations. Otherwise, there will be risk of distrust, suspicion and stigma. Understand fears around vaccination through constructive, participatory dialogue with affected communities, and come up with practical solutions as to address misinformation.

- Carefully consider who administers the vaccine and who carries out the community consultation and engagement, given the socio-political context, particularly in relation to local power structures and distrust of international and non-local national responders: there is a need to use trusted mobilisers.

- Consent should be sought, from both individuals and communities, to ensure the vaccination trial has broader support. The consent procedures should be designed to fit the communication and information needs of the affected people. This might mean translating the consent procedures into the local languages, making use of visual communication and reading the consent procedures aloud rather than giving the paper to the patient to read. Opportunities should be given to people to ask questions prior, during and after the vaccination process.

- Post-vaccination it is important to have a dialogue with vaccinated people about the long-term results of the vaccination, their rights and obligations as trial participants and to discuss any other questions that communities may have with regards to the vaccination procedure.

- Track emerging issues and rumours during the rollout of the vaccination campaign in order to address them proactively through communication and engagement with community leaders.

- Communities involved in the trial should be properly appreciated for their willingness to participate in the experiment, ideally by the international community or the Ministry of Health.

- Those women who have been vaccinated and lost their children during the Ebola outbreak should be provided with free medical and judicial support.

Building capacity

- Make use of the existing anthropological literature around the area and of previous responses to Ebola in preparedness activities: mapping this information in advance for risk-prone areas. Deploy social scientists at the onset of the outbreak to give inputs to initial activities.

- Establish community emergency plans (e.g. establishing who pays for transport and food, where quarantining can take place and so on) may help in preparing communities in advance for an outbreak.

- Provide aftercare for people who were vaccinated, especially women; during the Ebola crisis and now have health care problems (whether or not these problems are the results of the vaccine). It is also important to communicate that the vaccine is not a 'magic bullet' for all existing diseases but just protects against the Ebola virus.

8. Communication

Trust that is built on bottom-up approaches with communities, and that respect their local perspectives is necessary before communication efforts can be effective. The quality of engagement and two-way communication is as important as the content of risk prevention messages. It is important communities are listened to.

The West African Ebola response successfully tapped into already existing community engagement platforms, for example the networks of religious leaders in West Africa, as a way of 'gaining entry and trust in communities' (Gillespie, Obregon et al. 2016: 634). Further, existing participatory community networks on public health, such the one addressing open defecation in Liberia, were mobilised successfully with the provision of capacity building to address Ebola concerns (ibid.). UNICEF's experience was that the recruitment of local mobilisers enabled the response to have access to local knowledge and a deep understanding of the context. The best results were obtained when two-way communication was established, and the communities were providing the solutions (ibid.). This two-way communication is particularly important since (i) the epidemic draws different challenges at different stages e.g. at the onset, in the peak of the epidemic or in the aftermath, and (ii) people's attitudes and priorities shift as a product of their relationship with the disease and the response itself. Therefore, communication media and content should constantly be rethought and redesigned. Communications in Ebola often need to counter misinformation and exaggeration from the media. For example, there was a good experience of tracking perceptions and rapid response to false Ebola information through SMS messaging in Liberia (Internews 2015). It is important to note that policing and banning alternative non-biomedical explanations may drive them underground. For example, in the Uganda outbreak in 2012 people who spoke about witchcraft explanations were singled out and threatened with punitive measures, yet the discourse went underground but never disappeared (de Vries, Rwemisisi et al. 2016). Rumours, or misinformation, cannot be ignored or suppressed but must rather be openly discussed as part of the two-way dialogue between the response and communities.

UNICEF engaged with religious leaders, chiefs, healers, mayors and councillors, and other community leaders, through direct engagement or through media such as radio, and these partnerships proved to have potential for sustainability. That said, the recruitment of these traditional structures, sometimes eclipsed the voices of marginalised groups, such as women and children (Gillespie, Obregon et al. 2016: 632). It is important not to take for granted 'the community' and 'community leaders' but rather 'a critical step is to begin with a more realistic account of local social relationships...A 'one size fits all' approach and public meetings with supposed key stakeholders is not enough' (Wilkinson, Parker et al. 2017: 5-6). Trusted people by the community may not necessarily coincide with official or self-appointed leadership. This is complicated by the fact that different

people within the community may find different local people trustworthy. Further, it is important to understand that what constitutes 'being local' is complex: for example, urban volunteers doing outreach in communities were perceived as 'foreigners' (Gercama and Bedford 2016). In cases like Guinea, the historical distrust of outsiders extends to those who collaborate with them, making local alliances difficult. As such, anyone who agreed to work with the response as a representative of the community was not to be trusted, even if they were trusted before their agreement to collaborate.

In places where trust in local governance structures have been weakened by mass violence and killings, ready-made authority mechanisms might not be available. In North Kivu, for example, it was noted that rebuilding certain political relationships between the government – leading the Ebola response – and other local leadership (for example, political opposition, leaders or armed groups) may take time. As such it might also be worthwhile to engage with local civil society associations and associations of business owners, focal points for (informal) trade networks and farming organisations (Bedford, 2018f).

Messages need to be accurate, practical and relevant. Communities contrast their empirical and first-hand experiences with the messages they receive. In the Ebola outbreak in West Africa, a lot of messaging revolved around bushmeat consumption. When communities saw people keep eating bushmeat and not become infected, they distrusted public health messaging as a whole. In the Ebola outbreak in Uganda, some people saw cases with milder symptoms in comparison to those broadcasted as Ebola symptoms, and then discounted the messaging (de Vries, Rwemisisi et al. 2016). Communication efforts will also need to be understandable and as such should be delivered in the local language of the affected population. Bedford (2018i) noted friction between the response and affected communities in the Grand Nord when Lingala or Tanzanian or Kenyan Swahilli was used in communication efforts. Another civil society leader reported a different challenge related to language: '... If you are sick with Ebola, but you don't speak English, you have no way of accessing the team! How will you get information?'.

Response efforts should also respect local procedures and practices including presenting oneself to the right levels of authority; following protocol and being accompanied by the right people in the affected areas. (Bedford, 2018i)

Community resistance can be caused by an inherent lack of information and community engagement. Integrating social science knowledge into medical responses could help dovetail some of these challenges.

Messaging also needs to be understandable and attractive, hence meeting the delivery needs of affected populations. This is particularly important as public health messaging is competing with many other Ebola messages (e.g. from pastors, from the internet, from political opposition) that might be more appealing albeit less accurate. Positive, supportive and hopeful messages that emphasise 'togetherness' are most effective. Santibañez, Siegel et al. (2015) recommend clarity and conciseness, a maximum of 1-3 points in each communication, jargon-free, simple language with appropriate translation for local languages, recommendations framed in positive and practical terms (emphasising what to do, rather than what not to do) and through engagement at multiple levels (2015)[6].

Misinformation can have a potentially devastating impact on the Ebola response. In North Kivu and Ituri misinformation continues to circulate in the local media and is causing resistance against the response. 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. In recent online articles and radio interviews, for example, it has been suggested that Ebola was 'manufactured' for 'medical terrorism' (Bedford, 2018h). Political leaders have taken notice of the population's fears and use this narrative to further sow unrest and fuel hatred towards the government. Opposition supporters may state that Ebola is fabricated by the government to stop the elections (Gercama, personal communication).

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[6] For further information on communication for behaviour change in the context of Ebola see Figueroa (2017).

Social groups within Ebola affected countries and communities are very diverse, have different cultural understandings of the disease, and are affected very differently by Ebola and the response. These can be different ethnic groups, people with different economic or educational status, or explicit categories such as survivors, pregnant women or fishing communities (Gillespie, Obregon et al. 2016). Decentralising programming allows for a deep understanding of the context, and tailoring of messages for the different groups affected (ibid).

UNICEF saw mass media (e.g. radio), using tailored messages and language, work best in rural areas 'with reinforcement from interpersonal approaches (e.g. chiefs, religious leaders, community groups)'. In urban areas it was harder to tailor messages due to the diversity of populations, and interpersonal approaches were more labour intensive (Gillespie, Obregon et al. 2016: 632). In Liberia, 'town criers' played an important role in getting messages to illiterate populations. However, there is a gap in knowledge about appropriate approaches in urban areas specifically, and there is a need for further research in seeing what works and evaluating ongoing urban crises.

There is also a significant evidence gap in how best to reach affected communities in dangerous, off-limits conflict affected communities. Bedford (2018f) noted that armed groups do not live in isolation but have extensive domestic and transnational connections with local authorities and certain officers in the national army, local political authorities, economic figures and resource industries, it might also be possible to reach these groups through these channels, if negotiated in a diplomatic manner. If that would not be possible, the idea was offered that information pamphlets would be dropped in remote areas using MONUSCO logistics (e.g. helicopters) and that it might be possible to make use of established networks (including research networks) on the ground to distribute IEC materials to combatants.

Mobile phones can be effective communication methods in conflict affected areas if coverage is stable. Mobile phones are an important, if informal, way of building and maintaining social networks, conveying information and transferring money. They have the potential to mitigate social inequalities, political conflict and safety concerns, but meaningful use can found to be limited due to practical reasons including patchy network coverage and limited access to electricity to charge phones (many rely on generator-charger shops to charge their phones). However these platforms need to be approached carefully: mobile phones in North Kivu, for example, can serve as a security mechanism and early warning system although they are also used to coordinate attacks and demand ransoms etc. It was also noted that armed groups may view mobile phones with deep suspicion and have confiscated devices from community workers (Bedford, 2018h).

Existing social media networks, internet networks and other new media channels can also be harnessed to spread messages and to set up dialogue mechanisms with the affected communities, particular in hard-to-reach areas. Communities in North Kivu, for example, source and receive information through internet or WhatsApp group texts, including alerts about security incidents, activities of armed guards, and now, (informal) notification of new Ebola cases. Although it may seem impersonal, WhatsApp may be an efficient and effective platform for sharing regular information with families (Bedford, 2018h).

When Ebola messaging was incorporated into communications regarding several public health concerns (oro-faecal diseases, malaria, and so on), there was not enough Ebola information available, and people were more likely to ignore them. Thus, there is a tension between addressing Ebola effectively and maintaining positive behaviours for other diseases (Gillespie, Obregon et al. 2016). As in other epidemics, knowledge by response workers about the specific outbreak and how it is spreading carries a degree of uncertainty and emergence. The health authorities have to be honest about the limitations of their knowledge, making clear to the public about what is known and what is not, in order to maintain trust.

Knowledge on its own does not change behaviour: changes in practices occur when meaning is attached to the new practices. For example, the success in changing burial practices did not solely occur because of increased awareness of Ebola transmission risk but also because alternative practices were collectively

meaningful, allowing for mourning and supporting the spiritual transition of the loved one from the realm of life to that of the dead (HEART 2014). In Richards' words:

> The most fundamental drivers of behavioural commitment is the collective emotional state triggered and shaped by a ritual performance...it will not be possible to prevent risky behaviour such as participation in burial services by outlining the medical risks. This type of action will change, in terms of its epidemiological effects, only when risky practices are replaced by ritually and emotionally meaningful equivalent safer practices (2016: 19).

Messaging needs enabling infrastructure to be effective. As seen in past epidemics, messaging pushed people to wash their hands but with no clean water points available (de Vries, Rwemisisi et al. 2016), people were asked to wash with a bucket or keep a cup for each patient. However, they might not have access to either (Richards 2016). There are other constraints that shape enactment of recommendations that lead to problems if left unconsidered e.g. telling people to go to a location where their ethnic group is not welcome or directing them to a health facility in an area that is not secure.

It is also important to strengthen community dialogue and to provide more detailed information that goes beyond the repetition of basic messaging. Although improvements have been been in the most recent Ebola response, the flow of information often remains largely one-directional – from the response to affected communities – and not the other way around. 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. 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; b) can provide the response with operationally useful information, and c) can establish the credibility of response agents in the eyes of the community (e.g. through their ability to answer questions important to the community in a convincing manner). Facilitating true dialogue requires specific skills and expertise that should be strengthened across the response (Bedford 2018h).

Trust of the health system and the response

Regional and ethnic histories will determine the trust in the explanation and recommendations communicated by the response: In Liberia, people living in the forests were suspicious of Monrovia due to past 'pacification efforts' (and forest regions participation in rebel movements) (Richards 2016). In Sierra Leone, the system of colonial and postcolonial governance has been indirect rule through local leaders. Networks of patron-client networks exist between the centre and periphery of the country. Hence, largely, after initial resistance and riots, the response was able to operate through these systems of governance and their local legitimacy. However, rumours of corruption and moneymaking remained (Wilkinson and Fairhead 2017). In Guinea, the history of direct and authoritarian rule of the French colony and subsequent post-colonial governments meant that people in Ebola affected areas (e.g. the forest region) saw the centrally managed response and their local representatives as 'outsiders'. In Guinea, rumours of ethnic genocide were persistent throughout (ibid.).

Suspicions that the funding for Ebola is funnelled to corruption is commonplace, especially as people hear about large sums of money but do not see the Ebola investment at the level of the communities (as in the case of the Uganda 2012 outbreak). There were conspiracy theories that stated that Ebola was an exaggeration to fund medical staff (de Vries, Rwemisisi et al. 2016). There was 'disillusionment with competition and bribery in government hospitals. There is also distrust in the community health care system because it privileges the better off. (de Vries, Rwemisisi et al. 2016). In the ongoing outbreak in North Kivu, DRC, similar disillusionment with the government was reported and the response was blamed to not have any stake in stopping the outbreak: 'they don't want it to finish... they came to make money'. There are also numerous reports that

local health workers and vaccinators are being paid significantly less than personnel coming from Kinshasa ('those Lingala speakers') to work on the response in North Kivu. 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 (Bedford 2018h).

Communication recommendations:

Operational

- Accurate, relevant, understandable and practical messaging, that takes into account local understandings of the disease and practical everyday challenges. Messages should offer practical, actionable recommendations, framed in positive terms, and conveying hope and a sense of 'togetherness', be available in the local language.

- Mobilise trusted local community or social group members for community engagement. Ask a cross-section of the community who they trust and check for inconsistencies between official and self-proclaimed 'leaders' and nominated trusted people. Survey in parallel, the communication needs and preferences of the different social groups affected. Make sure that the right procedures and local courtesies are followed before and during engagement activities.

- Adapt programming to local contextual factors, as different contexts within the affected areas will require different types and content of communication.

- Material support on top of information: many households do not have the resources that may be necessary to 'enact' risk mitigating behaviours: e.g. bucket, cups, disinfectant, protective equipment, and so on.

- Tracking community perceptions and alternative explanations of the virus and the response rather than rumour-busting. Follow the perceptions that circulate amongst communities and their leaders and change the messaging accordingly, or modify material aspects of the response if relevant (e.g. providing food, water for community quarantining). Avoid 'forcefully denying' existing beliefs as they may go underground.

- It is also 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 lead, but should also be integrated and operationalised across other pillars within the response through the IMS and other relevant structures.

- 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 channelled to have the greatest impact.

- 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 fairly and that recruitment processes are made transparent.

- An analysis of the context should yield who is at risk of being stigmatised by Ebola: survivors, family members and health workers, but also social groups that may be portrayed as 'carriers' of the disease (particular ethnic, nationality or other social groups) or as the 'cause' of the disease (street children, widows).

- In case communities cannot be reached through interpersonal approaches due to the safety and security concerns, explore harnessing platforms and mechanisms that communities already use (local media, WhatsApp, church networks etc.).

- Messages around intimate physical contact 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.

Building capacity

- Create long-term partnerships with relevant local authorities: local elites, health system authorities (national, provincial, district and zonal), administrative authorities at all levels, customary authorities (e.g. chiefs) and socially significant individuals in the area (e.g. healers, midwives). Please note that these authorities are contested and changing, and that not all will be actually willing to support a government-led Ebola response. These partnerships can be established in an outbreak setting or as part of preparedness activities.

- Communication should evolve with the disease, acknowledging the 'dance' that happens between the response and the communities' learning and the stages of the epidemic: approaches and messages will vary (Gillespie, Obregon et al. 2016). For example, in the beginning of an outbreak work can be directed at demystifying ETC, and at the end concerns may be addressed about fears for the continuity of health service, risk re-emergence of disease and persistence of the virus in survivors.

9. Health system capacity and treatment-seeking

People are pragmatic in seeking care: they will try different courses of action to find a cure and caregiving strategies 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). It is important to promote that, when they understand the risk of transmission, communities are best placed to suggest acceptable modifications to local care practices and health-seeking behaviours (Bedford, 2018h).

Access and quality of biomedical care

Often 'weak health systems' have been portrayed as the cause for the inadequate response to Ebola in West Africa. Abramowitz notes Farmer's assertion that there were four things necessary to be able to do something about an epidemic: 'staff, stuff, space and systems', and in Sierra Leone these were not met. Abramowitz indicates 'staff shortages, corruption and distrust in the 'free' maternal and child health care undermined Ebola response efforts' (Abramowitz 2017: 432). Yet the technical discourse of weak health systems ignores decades of structural violence, a confluence of 'long term economic, social technical discursive and political exclusions and injustices' (Wilkinson and Leach 2015: 137). The symptomatic treatment available today (e.g. intravenous hydration) and the isolation of patients in treatment units can be done with little resources

Lessons Learned

(Richards 2016). That said, even basic resources such as running water in hospitals or personal protective equipment were lacking and in some settings in West Africa not even basic Infection Prevention Control (IPC) was possible. Further, the standard approach is that specially engineered infrastructure to keep patients and staff safe is constructed *de novo*. Tents are not expensive, but neither are they pre-existing infrastructure available at only opportunity cost. The protective equipment used is relatively expensive by the standards of the countries affected by Ebola.

Experimental treatments are being currently administered in the recent DR Congo outbreaks, under a compassionate use framework developed by the WHO, known as Monitored Emergency Use of Unregistered Interventions, or MEURI. The Ministry of Health has approved the use of antibody treatments (such as ZMapp) and antiviral drugs (such as Remdesvir). Some of these treatments had been used in the 2014-16 West African epidemic (for more detail see WHO 2018). Many of the ethical and social science considerations described for vaccinations above would apply to the roll-out of these trials.

Health care in countries affected by Ebola is often underfunded and people often need to provide their own medicines, sheets, food and transport. As shown above, transport costs are crucial in decisions to reach out to a clinic when someone contracts Ebola. Those on low incomes often delay going to the clinic or rely on homecare. In some cases, for example in Sierra Leone, the father's family pools together resources to send the person to the health centre, and if there isn't enough, they would sell the patients land or assets to enable this (Richards 2016). Illness is a family (and communal) affair, with family members accompanying and visiting family members in the hospital. Family members play an important role in solidarity, love and companionship as well as 'an important logistical role...providing food to the patient (meals are not provided by facilities), giving additional personal care, negotiating their treatment (including payment) and advocating with health workers on their behalf.' (Bedford 2018: 1). Hospital visits by family members' have sparked transmission of Ebola, yet biosecurity measures cannot mean disconnecting the person with their family. In the past, people would choose not to attend an Ebola Treatment Unit if they thought they would not be able to receive visits. Ebola treatment spaces should ensure means of communication with family and ways in which people can see family members.

In conflict-affected areas access to healthcare centres can be blocked by violence and/or the associated fear with violence. In North Kivu, for example, the ongoing conflict has had a detrimental impact on access to healthcare, and the health system is fragmented and politicised with recent attacks reported on pharmacies and hospitals. 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. Many healthcare professionals are no longer able to operate in areas in North Kivu. At the same time, health care providers may be one of the most trusted actors for healthcare advice. For example, in North Kivu, DRC despite the weak health system and persistent challenges in accessing health facilities, high levels of trust in health services and health workers were reported prior to the Ebola outbreak, particularly in urban centres (Bedford, 2018h). Practical matters also may prevent communities from accessing care including roadblocks set up by armed groups or rebel forces (Bedford, 2018g).

Members of militias or armed groups may also experience specific barriers for care. It is possible that the threat of arrest may prevent members of armed groups from seeking care or allowing the safe passage of others. At the same time, health-seeking practices of armed groups can increase insecurity and heighten the risk of transmission. It has been suggested that members of armed groups may cross the border to seek treatment at trusted hospitals although again, further investigation is required. 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. These type of challenges must be discussed locally and appropriate solutions must be agreed on (Bedford, 2018g). One potential option is negotiate an amnesty for combatants who bring their fighters to care centres during the outbreak, but this is logistically difficult in many settings.

Other health providers

Different contexts will have different health providers available that people will seek treatment from (on occasions in sequence or combined).

For example in the case of Liberia, the following providers and health-seeking behaviours were identified by the population in the 2013-2015 epidemic (Abramowitz, McLean et al.):

- Home care

- Herbalist healer

- Traditional healer

- Faith healer

- Ebola team (who would, if possible, pick up the patient in an Ebola ambulance)

- Doctor or nurse through social networks

- Clinic

- Drug vendor/pharmacy

Note that the trust in each one of these health providers varies with the context. In Liberia, 'Liberians are almost twenty times more likely to seek medication from pharmacists, drug vendors, and petty traders than they are likely to seek treatment from a clinic, a hospital, or even from a traditional healer…Liberians accept Western medicine, especially pharmaceuticals'. Thus, the dominant culture for health-seeking in Liberia is market-driven (Abramowitz, McLean et al.). Alternative health providers are likely to visit infected patients and households and are therefore, a potential vehicle for Ebola transmission, yet they are also 'potential resources to prevent disease and spread and communicate with local populations (Shilue 2015)' (Abramowitz 2017: 432). In North Kivu, as elsewhere in the DRC, it is important to determine the cause of illness, and local healers are often consulted and respected 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 (Bedford, 2018h).

A positive development has been the proactive engagement of alternative frontline providers of care in the North Kivu outbreak (2018-ongoing). 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 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 (Bedford, 2018h).

In conflict-affected areas international relief organisations may also be 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 (Bedford, 2018h).

Ebola survivors in past epidemics are believed to be immune to reinfection (unlike in some other diseases). The responses have often recruited survivors as health workers for this reason.

Specific Ebola treatment

Prior to the West African Ebola outbreak, the model for Ebola case management was isolation in a hospital and ideally a specially constructed isolation unit. The magnitude of the West African outbreak, when isolations units could not be built fast enough and in large enough numbers, led to diverse strategies in case management.

Three approaches to Ebola management materialised: Ebola treatment centres or units, community care centres and home care.

Ebola Treatment Units

In the first phases of the response, Ebola treatment centres in all three countries were stretched beyond capacity and were forced to turn away patients at their gates. This disincentivised attendance.

Despite ETU's being free, costs also determined patients' capacity to seek treatment in an ETU: in remote areas the cost of transporting a person to a centre is high: hiring people to transport the person, the food involved on the journey and so on.

The relative remoteness of home villages from the ETU, particularly when mobile coverage is poor, may mean that there is little knowledge of what happens to the family member once they are picked up by the Ebola ambulance. This lack of knowledge, unless it is redressed, can lead to misinformation and conspiracy theories.

Ebola treatment units that had opaque tarpaulin would also generate distrust, as if they had something to hide, hence fuelling conspiracy theories of body snatching and experimentation in outbreaks until the 2000 Gulu outbreak in Uganda. (Hewlett and Hewlett 2008, Richards 2016). For example, in the Isiro outbreak in Congo, in Haut-Uele province in 2012, the high mortality rates of Ebola and the lack of information to family members of communities at the onset of the epidemic meant people described ETU as 'death camps' and would fear seeking treatment in them (Gomez-Temesio and Le Marcis 2017, Bedford 2018). Fear for ETU's had also been recorded in Equateur and in North Kivu and Ituri, DRC. The perception that everybody who goes to an ETC 'will surely die' and the joint fears of isolation and the unknown were clearly articulated in community narratives. Alcayna-Stevens (2018) however, notes that the perceptions of populations may change over time, particularly when the care that has been provides is of high quality.

Community and stakeholder 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 Equateur (2018), the NGO 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 support. 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.

Community care centres

In response to both the lack of ETUs and apparent resistance to being treated in the ones which had been built, alternative treatment models were considered during the West African epidemic. 'Community Care Centres' (CCCs) were a community-based model. CCCs which provided free health care, food and testing resources within communities, were enormously popular and effective as a first-line triage system. (Abramowitz 2017: 431). These were found to be more culturally appropriate, and people were more likely to entrust their ill family members to trained workers in the community. That said, community care centres were rolled out late in the outbreak and whilst post-crisis reviews are positive, their appropriateness and their safety was highly contested during the response. It is important to highlight that community care will be relevant or not depending on the context, it will be an adequate strategy for care provision in some cases and not in others.

Risk has to be assessed and trade-offs calculated. CCCs involve less risk than an unmanaged outbreak, but are, medically riskier than care in a well-staffed and well-run ETU. Because there is a risk of death for people caring for Ebola patients, passing this risk to the community (rather than to trained and equipped health staff) must be a considered decision.

The closure of community care centres after the end of the epidemic is also a sensitive issue: in Sierra Leone, communities involved in CCCs had been constantly receiving messages of local ownership, but at decommissioning, most valuable assets and stocks (motorbikes, generators, and medication) were returned to the donor. Some materials were to be transferred to the departmental health centres. This created conflict between communities, response workers and the health centres (UNICEF 2016: 30). In Equateur, in DRC, similar challenges were recorded and culminated, post-response, in a scramble between various government departments, politicians and local communities for the remaining resources from WHO and UNICEF (Alcayna-Stevens 2018).

Home care

Home care for Ebola was first used in the 1976 outbreak in South Sudan. 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. The need for homecare can be driven by patient refusal to attend ETUs. Homecare is both complex and controversial, but may be the only feasible option 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).

Ebola is a particularly challenging disease for communities as it goes against the usual principles of good care. Infection control measures may clash with the responsibility of people to take care of their family members. People in West Africa demanded more capacity to care for family members at home and have protective equipment given to families (Wilkinson and Leach 2015, de Vries, Rwemisisi et al. 2016). The reality was that people ended up requiring home care anyway, either because clinics were unavailable (physically or economically), or ETU's were turning people away (or people did not want to use them). Communities demanded support in providing care at home, asking for advice, training and equipment for homecare. The Ebola response platform (ERAP) supported these initiatives, since training for appropriate home-based care had yielded good results in the Congo (Hewlett and Hewlett 2008). However, there was unease within the response to be seen to endorse 'suboptimal' safety for the family and caregivers and a debate emerged about if and how to do this. This meant in some settings it was recommended and supported (e.g. with the distribution of 'home care kits') whereas in others it was not encouraged and neither information nor equipment was provided. Over time, with the realisation that people were doing home care anyway, communication strategies adapted to the situation with messages like 'what to do while awaiting help' that could apply to home care (e.g. keeping the patient hydrated, disposing and disinfecting fluids, keeping distance and so on). MSF in Liberia also provided hygiene kits to high-risk communities, particularly when ETU's were full. Homecare also allows to build trust with the emergency response and some patients would then agree to go to ETUs when symptoms

When isolating patients at home or in community centres, there needs to be a system in place for provision of food. At the onset of the West African epidemic, some people who were isolated fell hungry because there were no systems in place to deliver food (Wilken, Pordell et al. 2017). Provision of food was a main concern for people when committing to isolation (Abramowitz, McLean et al. 2015).

Lessons Learned

Health system capacity and treatment-seeking recommendations:

Operational

- Understand who the relevant health-providers are in the current context and what their models of disease and treatment are (drug sellers, traditional healers, faith healers, and so on). Engage with these providers early on, harnessing their influence rather than resisting it. These healers can be enlisted for Ebola messaging, to support surveillance and encourage referrals to biomedical clinics or community care centres of Ebola patients.

- Provide these alternative health providers with information on transmission and risk behaviours and provide protective equipment.

- Understand how people understand Ebola, its cause, prevention and transmission, and in that context, engage in a dialogue with communities to ascertain what is considered to be 'appropriate care'.

- Consider delegating care as much as possible to the communities when appropriate if they are willing to do so (and this has been often the case), training and enabling communities to manage triage, isolation and treatment.

- Maintain a transparent process of identification, triage, isolation and treatment to reduce rumours. Appraise and track willingness to use Ebola health services and willingness work with response teams and surveillance and contact tracers. Explanations should be couched in local explanatory models.

- Work with trusted community members to reduce and mitigate rumours about Ebola treatment units, engage with those actors spreading false information to reason and negotiate a change in reporting.

- 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. 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.

- Community engagement activities should stress that anybody with potential signs or symptoms of Ebola should go directly to their nearest ETC.

- Engage specific social groups within communities directly whenever relevant (e.g. women, indigenous people, young people, and so on).

Building capacity

- During large epidemics when formal treatment options are limited, give households the practical skills, recommendations and material resources (personal protective equipment and other relevant equipment) to carry out home care of patients – although not ideal it is likely to occur anyway.

- 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).

- 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.

10. Burial practices

When a person has died from Ebola, their body and objects they had been in contact with (clothes, bed linen, and so on) may remain contagious for days. This means that preparing the body for burial, the actual burial, as well as the congregation for funeral and other mourning rituals are high-risk events for Ebola transmission. The risk is highest in the preparation of the body.

Burial practices are a salient example on how a positive relationship between the response and communities can shift practices, which meet public health goals and the needs of communities. In the West African outbreak, there was a shift from a medicalised burial to a safe and dignified burial (SDB), an approach that is still used in ongoing Ebola crises today. At first, the Ebola response in West Africa took a punitive approach to burial practices: for example, Sierra Leone made the washing of corpses a punishable crime of up to two years in prison (Richards 2016). In the onset of the West African epidemic, even when people sought 'safe burials' organised by the response, the caseload was so high that corpses rotted in the streets (Martineau, Wilkinson et al. 2017). Lack of organisation of the response meant that corpses were left unburied and ETU's did not inform families in a timely manner when ill relatives had died (Abramowitz 2017). Often the identity of the person and the contact details of the family were unknown. People in charge of cremation were unable to separate the ashes of the deceased and did not know what procedures to follow for burial. The treatment of dead bodies as 'infectious' material (rather than as family and community peers transitioning from the realm of the living to the dead) was seen as inhumane. Either because of necessity or resistance towards culturally insensitive safe burials, large numbers of people buried their loved ones' bodies following the customary protocols, which ended up increasing the spread of Ebola.

Burials have to be simultaneously safe, dignified and meaningful. Burial and funerals play a social role as much as a practical role of putting a body in the ground. For example, in burial practices in parts of West Africa often include procedures to distribute inheritance and ensure the deceased an afterlife. Burials and funerals also play a psychological and emotional role, as an important part of a grieving process. Burial and funerals 'symbolise the deep connection between the deceased person and their socio-cultural networks' (Bedford 2018). Failing to conduct funerals appropriately may cast family members as negligent, or foster suspicion of malicious causes of death' (Chandler, Fairhead et al. 2015: 1275). For example, amongst the Acholi, if the burial was inadequate, the 'deceased person's spirit (*tibo*) will cause harm and illness to the family' (Hewlett and Hewlett 2008: 55). In the case of West Africa, many large-scale funerals (which are high-risk events) were managed by the Poro and Sande sodalities, societies of elders who did not make the burial procedures public knowledge. Only members where aware of the specifics. Hence, engagement with the leaders of these sodalities proved crucial to negotiate changes in burial practices (Richards 2016).

Moran (2017) cautions against anthropologists (and the rest of response workers) narrowly seeing mourning and funerals as rituals with symbolic importance, and shows that 'the emotional impact of loss and bereavement' cannot be ignored. Grief, rage and despair accompany death, and these cannot be met solely with changing rituals but also an acceptance of bereavement (ibid.).

Preparation of the body

Body preparation is significantly more infectious than attending a funeral. Social structure, culture and religion all determine who washes the body, prepares, dresses, and decorates it for the wake and burial. There is a high variability of burial practices within African countries, and hence there is a need to contextualise the discussion of risk prevention to each context. As mentioned above, in some situations it will be the husband's family who are responsible for burial, whilst in others it will be the paternal family of the wife who is in charge of burying the patient. This will determine in which village the body is buried and by whom it is prepared.

Body preparation practices are imbued with meaning, even ones that may seem small. For example, closing of the eyes and mouth of the patient is socially significant. In this context,

People speak about severe sickness as being a time for the disclosure of hidden matters. Confession in such circumstances is thought to be advisable, even healthy…But the secrets of those close to death are handled with greater discretion. The eyes and mouth are closed by the wife or husband, or by the eldest child, because the person should be mature enough to keep the secrets of the dead (Richards 2016: 100).

The preparing of a body is often managed by certain family representatives, which are at more risk than other family members. In North Kivu, for example, there is a gender distinction in that men will wash a man's body, and women will wash a woman's body (Bedford, 2018g). The body of the deceased is dressed in good clothes prior to burial. Ideally, men will be dressed in suits, and women in *kitenge* cloth. (Bedford, 2018g). For many communities it is important to discern the cause of death, so this can be explained when the death is formally announced. In North Kivu, it is usually the patriarch of the family who must deliver the reason or most plausible explanation of death. Doctors are trusted and many families accept medical explanations for causes of death. In other cases, metaphysical explanations are offered (e.g. death as a result of curse or divine or ancestor disfavour), or a combination of both (Bedford, 2018g).

The way the body is placed may be different across communities – it can be placed in a coffin for burial or wrapped in cloth, etc. In villages and rural areas in DRC where coffins are less readily available, and often the body can be wrapped in cloth. Muslim communities also wrap the body of their deceased in cloth but do not use a coffin. The cloth that is used to carry the body to the burial site (as opposed to the cloth that the body is wrapped in) is often retained by the family (Bedford, 2018g).

Body preparation rituals can change over time. In North Kivu, in preparing the body for burial, some families still wash the body, but this practice is less common than it was. Rather than washing a body, it is increasingly common for families to use a spray perfume to prepare or anoint the body in preparation for burial.

Part of the burial team's tasks is to disinfect the household after death of the patient. This process can raise a lot of resistance: for example, the use of chlorine for disinfection raised rumours that people were being poisoned. Similarly, the practice of burning clothes and sheets of the dead seemed to many as traumatic. In response to this, in subsequent burials, the clothes of the deceased were put inside the sealed coffin and that was more acceptable (Richards 2016). However, people also inquired if they would get clothes and sheets to substitute them, and wondered if leaving them outside for several days would be enough to kill the virus, yet messaging did not address those practical matters (ibid.).

Use of body bags: the challenge is to show the purpose of them in containing the infection. Further, the colour is important, at first in Sierra Leone the body bags were black, when the colour of shrouds are white, and people resisted using them (Unnikrishnan and Bedford 2015). The symbolic role of the cotton shroud is very important, in Sierra Leone it is washed in the river after the burial, with the dilution of dirt as a way of seeing the dead person move away from the living, and then it is kept by the youngest son in his room. This symbolic requirement would need to be addressed in alternative ways (Richards 2016). In North Kivu, some community members suggested that it may be acceptable to 'see' the body through a body bag as this would allow them to see the form of the body without being at risk of exposure, but this requires further investigation. Transparent body bags would maybe help mitigate fear around the 'stealing of the corpses', which local population says is being done by response actors (Bedford, 2018g).

Transport

As mentioned above, social structure may determine women having to be transported to their hometown. Similarly, people (men and women) in cities often feel strongly attached to their home villages, and wish to be buried there. For example, dead bodies are often transported in Mbandaka in Equateur to the villages to be buried in clan cemeteries. This movement of bodies was suspected to play a role in Ebola transmission. In North Kivu, it is also not usual to leave a body at the hospital. The body of the deceased is brought to its home or the home of the family's patriarch. There is usually one night between the death and burial, and it is expected

that the body will remain at home during this period (Bedford, 2018g). Being buried in clan cemeteries maintains a claim of the family to their land and decision-making in the villages (Bedford 2018 a, b). In West Africa, by the end of the epidemic the safe and dignified burial teams would take bodies to be buried in their hometowns.

In conflict-affected areas it might not always be possible to bury the body in the natal village of the deceased. In North Kivu, for example, although burials would customarily be in the deceased's ancestral land alongside their relatives, ongoing conflict, insecurity and displacement in the *Grand Nord* have required communities to negotiate new practices, and many people are now buried in the place where they live. This is hopeful as it highlights that burial traditions can be modified if needed, in order to comply with safety and security needs (Bedford, 2018g).

Burial

Note that safe and dignified burials are necessary for all deaths, not only Ebola deaths, since Ebola is circulating in the community and thus a concentration of mourners can lead to transmission amongst them (Richards 2016).

The length of burial ceremonies and the amount of time in between death and the burial may differ per community. In North Kivu, for example, the burial often takes place within 48 hours of death (Bedford 2018g).

Funerals are often important social events and friends and family are expected to travel home to be with the deceased, so it is normal for a large number of mourners to congregate. In North Kivu, on the day of the burial, mourners are usually offered food prepared by the direct family and close friends of the deceased. It is common for family and friends to gather around the body (day and night) to give their last respects, and symbolically grieve their loss. Crying or wailing is an important expression of grief. Family and friends will remain with the corpse overnight, sometimes eating and drinking together (Bedford 2018g).

In some cultures, such as in Equateur province in Congo, seeing the loved one's face before burial is important. Arrangements have to be made for the mourners to see the face of their loved ones. Seeing the loved one is also important to avoid rumours of body snatching. Further, the perceived cause of death also shapes the burial practices. For example, in Boende outbreak in 2014, if there has been suspicion of sorcery, the community would wish that organs, hairs, nails and clothes were not removed from the body for use in witchcraft (Bedford 2018d). In North Kivu 'seeing the dead' is also a significant component of local practices following a death. During burial rituals the deceased can be 'viewed', either in a coffin at the house, or in his/her bed. Other family members who did not participate in washing or dressing the body may choose to touch the body to feel close to the departed as they pay their respects, but this is not a required component of the mourning ceremony. Viewing the body is important, both as a way for family and friends to honour the deceased, and also to provide visual confirmation of death. Not being able to see the body may fuel fear and rumours around the intentions of the response (Bedford 2018g).

Young men are often in charge of digging the grave, sharing shovels and transporting the body into it, making them at risk of infection.

High status funerals are riskier because they need to be more 'traditional' and are attended by more people (Martineau, Wilkinson et al. 2017). In this context, it is socially important to 'host a good funeral', with greater pressure to conform to traditional norms including attendance of a large number of people.

Rituals and practices are not static, but 'living' and can change. For example, in Sierra Leone there was experience from the civil war of changing burial protocols. Anthropologists embedded in the West African response, engaged with communities to find culturally acceptable and meaningful burial rituals that simultaneously met public health goals. The ERAP platform also contributed to the writing of safe and dignified burials WHO protocols. (Martineau, Wilkinson et al. 2017). These protocols allowed for funerals to be led by religious leaders, for mourners to attend, at close proximity for immediate relatives and therefore already

exposed and not at close proximity, if a distant relative or friend. Communal hand washing of grave dirt was replaced in some contexts by chlorine water washing (Hewlett and Hewlett 2008). Personalising the burial as much as possible may also help remedy the psychological and emotional loss of the 'normal' burial process, although this needs to be further studied. Due to the security context of the *Grand Nord*, Eastern Congo, some traditional practices have rapidly changed or evolved over recent years. The ceremonial washing of a body after death for example has become less common, particularly in urban centres such as Beni, Butembo and Oicha. In honouring the preparation of a body for burial, it is growing practice to use spray perfumes instead of washing (Bedford, 2018g).

As mentioned above, the wrapping and dressing of the body is important and adaptations should be made to address that. In preparation for burial, it remains customary to dress the body in good clothes (suits for men and *kitenge* cloth for women). Ideally, family members should be able to provide appropriate clothes for the SDB or medical team to dress the body prior to burial (Bedford, 2018g). Similarly, there are requirements of what the body has to carry with it: particular possessions (e.g. shoes in DRC) or to be moist with their favourite drink, etc.

It is important to be sensitive to the fact that different communities in the same geographical area may not have the same burial practices. In North Kivu it was noted that Mbuti (minority indigenous) communities may have burial practices that may vary from those of majority community. For example, customarily, the Mbuti do not use coffins. Often the body is carried by hand to the burial site where a shallow grave is dug to enable the community to 'remain close' to the deceased. The displacement of many Mbuti communities and restricted access to forest land due to ongoing insecurities has resulted in rapid and often dramatic shifts in their customary practices. Whilst many may prefer to bury their deceased in the forest rather than in urban towns or designated cemeteries, this is often no longer a viable option and many of the practices described above are now followed (Bedford, 2018g).

Armed groups may also have specific burial practices. If armed groups are directly affected by Ebola, their burial practices may place the group and surrounding community at risk of transmission. In North Kivu, the following practices were identified which may be of relevance, although they may not necessarily directly relate to Ebola:

- Rank-and-file combatants or those who have been forcibly recruited are often required to dig shallow graves outside the camp for deceased armed group members. This protects rebel leadership while exposing the lower-level members of the group to infection.

- Many armed groups navigate between civilian and rebel life, and live close to or are embedded (socially, financially and geographically) with communities. In some cases, if an armed group is close to a village, they may conscript members of the surrounding communities to dig graves and bury their dead. Some groups would notify family members after a death and allow them to collect the body of the relative to be buried in the village.

- It is also reported that armed groups may leave bodies in the dense forest, or dispose of bodies in rivers (Bedford, 2018g).

Mourners often give condolences in particular ways and in some cultures, funerals are an occasion for gift-exchange. In the outbreak in Equateur in Congo, the community outreach team would partake in the condolences handing a small gift to widows and widowers. In Guinea, the WHO contributed to some ceremonies as a sign of respect to the deceased and the burial process, symbolically showing that the response understood the social meaning of the burial.

The ERAP platform recommended passing of responsibility for burials to communities themselves to prevent strangers to the communities and people of inappropriate ages burying the dead. Community burial teams would then receive training and protective equipment. This approach would enable burials to be as

context-specific as possible, whilst upholding public health objectives. However, this idea was largely rejected in the West African response, mainly due to feasibility and logistics rather than appropriateness (Martineau, Wilkinson et al. 2017). It was piloted in certain places, but there were limitations in resources, such as lack of personal protective equipment or petrol for transport, (Wilkinson 2018, personal communication).

Not respecting burial practices and traditions can have long lasting social and mental ramifications for individuals and communities. In North Kivu, for example, the Nande concept *'eirhola ndenke'* means that the family took care of the deceased and buried them correctly. *'Erihola navi'* refers to a body that was not correctly prepared or burial rites that were not respected or poorly conducted. If a burial is not conducted well, or to the standards prescribed by the community, it is thought that the deceased is refused the opportunity to rest in peace. As well as disrespecting the life of the deceased (and life in general), failure to perform a 'correct' burial can have negative repercussions for the family and community.

Mourning rituals

Much of the literature on Ebola focuses on body preparation and burial ceremonies. Whilst these are the practices that are typically most contagious, it is important to explore if there are other mourning rituals and death-related gatherings that can be a source of infection. For example, in Congo, there are family gatherings that follow burial that can take up to 40 days after the funeral, or mourning rites in different phases across several months (e.g. Balambo communities in Haut-Uele province) (Bedford 2018).

The mourning family may have obligations beyond burial. For example, in Boende (2014), the widow/er needs to be 'cleansed' by their in-law. 'He or she remains isolate and is not allowed to speak to others or wash themselves until after they have been cleansed. This practice may cause delayed care of other family members, particularly children' (Bedford 2018).

It is well documented that having no proof of death is compounded by the distress of not being able to bury a person in an acceptable way. In such scenarios, families and communities are vulnerable to 'ambiguous loss' in which the experienced loss is not verified, the grieving and mourning process is frozen and the natural human need for meaning, sense, knowledge, connection and ritual is denied. This void and the 'presence of absence' can have a continuing and devastating impact on everyday life and long-term mental health. Although 'ambiguous loss' is most often reported in conflict settings, it is also evident in communities affected by Ebola when 'normal practices' are disrupted, as when a person is admitted to an ETU and their family is not informed of his / her death before burial; the family cannot engage with the body (e.g. to view it after death) or be involved in Safe and Dignified Burial (SDB) practices; and/or the body is buried away from their community (Bedford, 2018g).

Adapting burial practices

Burial traditions are not static and communities, overall, show willingness to adapt and modify burial traditions, when engaged in the right way. The critical importance of involving communities in the adjustment of SDB protocols to ensure they are locally appropriate and acceptable, keeping family members well informed and facilitating their engagement with SDB practices, and providing additional sustained psychosocial support, cannot be over-emphasised (Bedford, 2018g). In North Kivu, for example, a willingness to forego large funeral gatherings was recorded if trusted family members are allowed access to safely view (not touch) the body (Bedford, 2018g).

It is important to note that, particularly in the beginning of an Ebola outbreak, challenges are often reported in regards 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 (Bedford, 2018g).

Burial recommendations:

Operational

- Understand beforehand what customary body preparation and burial practices are in place, and the meanings that are attached to these practices. Identify who is in charge of which task, and its social significance. Understand how social structure and other socio-cultural factors impact on who is responsible for preparation and burial and where the body needs to be transported to.

- Adapt burial practices to the specific practical and symbolic needs of the communities, as a product of a negotiation between burial teams and the communities. Acknowledge that local practices are not static, when communities understand the risk of transmission associated with preparing a body after death and with burial they are best placed to suggest modifications to those practices.

- Whenever possible, relevant, and desired by the family, provide safe transport and burial of bodies to their home villages, and provide families with the option to pick the place of the grave (e.g. beside their house, in the forest, etc.).

- Discussion and agreement about how a safe and dignified burial should be conducted is critical. Careful consideration must be given to who should be involved in such discussions from both the response and affected community and family.

- Create an opportunity for the family and other important, selected members of the community to visually view the body in a safe manner from a distance. This will help curb rumours around the 'stealing of bodies' and suspicion in the response which can cause fear and resistance against IPC measures. It would be useful to explore the use of transparent body bags for the Red Cross ambulances or have a member of the family/community travel with the ambulance to discuss with other communities, who may have concerns.

- Burials must be conducted by trained teams, as localised as possible, involving family and community-appointed representatives. Safe and dignified burial guidelines must be as similar to local burial and funeral practices as possible, only changing or adapting the components that are medically unsafe.

- Families of suspected, probable and confirmed cases should be engaged in discussion about what will happen in the event that their relative dies. The safe and dignified burial procedure at the local level should be carefully agreed, and opportunities provided for the family to ask questions and make particular requests, with careful explanations of what safety components are necessary. This will avoid the risk of surprise, suspicions and incorrect assumptions, and is likely to play important social and emotional functions as described above.

- It is important to include some space for burials to be personalised whilst maintaining safety. In cases where funerals are important for a display of status, personalised elements in the funeral can avoid hidden burials or hostility towards burial teams.

- Burial teams should include persons who already customarily play a role in death, burial and funerals and who are known to local communities (for example, religious leaders or traditional healers and leaders). Such individuals should receive training on safe and dignified burial protocols and procedures and should act as liaison between a family and burial team, even if they are not directly involved with making the body medically safe.

- Acknowledge that people who are part of burial teams, are expected to show empathy and connection, despite increased pressure and risk of stigmatisation. As such, their psychosocial wellbeing needs to be supported along with their knowledge and skills in supportive communication and provision of aftercare.

- It is critical that religious and community leaders as well as community engagement personnel in SDB teams, or health workers in a medical setting, clearly explain why it is unsafe to view the body more intimately.

- Families and communities should also be given clear information about how long the team will take to arrive, if they will be delayed and why, 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.

11. Post-emergency

For an Ebola outbreak to be officially declared over, two incubation periods (a total of 42 days) must pass without any confirmed cases. Unlike in influenza, the virus mutations have not created several waves within the same outbreak in the past.

Social and economic consequences: Trade and movement blocks, lack of investment, and hours lost to illness or care have important economic consequences that take years to recover from. In the case of poor Ebola affected households, the impact is particularly high. Expenses related to transport, food and assistance may lead households and kinship groups, when these are responsible for a kinsman's expenses, into indebtedness. This debt may translate into loss of land (Richards, 2016). The burden is exacerbated in the case of female-headed households and orphaned children.

Survivors' health: survivors are more likely to develop eye problems, blurred vision, hearing impairment, memory loss, lack of concentration, and sleeping problems (Clark, Kiibuka et al, 2015). The exposure to suffering and death for those cared for in ETU's and CCC's can represent a traumatic event (Rabelo, Lee et al. 2016). The long-term presence of the virus in the semen means surviving men are at risk of spreading the infection. The experience of survivors after Ebola: the loss of family members, employment, uncertainty over social status, and so on, can be as distressing as suffering the disease. It is important to highlight that there is still uncertainty regarding the persistence of the virus in survivors, as well as the longer-term social implications for survivors (e.g. stigma).

It is important to note that identifying people as 'survivors' for the provision of healthcare or aid can have negative effects in terms of their community integration, with people in affected communities yet who were not infected feeling like 'we are also survivors' (Richardson, Kelly et al. 2017).

Stigma: Survivors and health workers are at risk of being stigmatised and shunned by their communities. Survivors in the West African epidemic were often accused of spreading the virus, and bonds with family and communities were broken. Some survivors were chased out of their communities, were evicted from their rented houses or were in conflict with their family members (Arwady, Garcia et al. 2014). Further, in some countries survivors were told they would receive compensation, something that can raise rumour and jealousies in the communities. For example, cash transfer programmes for affected communities played a significant role in enhancing food security and wellbeing (Richardson, Kelly et al. 2017), yet were challenging in terms of communicating why Ebola (rather than other livelihood crises or illnesses) had been singled out as a requirement for receiving aid. The health response also aimed to support reintegration of survivors through the provision of Certificates of Medical Clearance and blood testing (Arwady, Garcia et al. 2014) and phased reintegration programmes collectively agreed in the communities (ERAP 2014). Using a 'resilience' lens (e.g. building on collective strengths and practices) rather than a 'trauma lens' (e.g. counselling individuals with trauma) avoids victimisation and generating feelings of vulnerability, and instead reinforces feelings of autonomy (Jones, personal communication). There is a gap in research recording positive community engagement experiences in the reintegration of survivors into communities, learning what strategies worked best.

Health systems: will need time to return to normal, making up for the closure of units, and the loss of a significant number of health workers. In terms of community engagement, the decommissioning of health units can raise anxieties about (i) whether those funding efforts will be redirected to other immediate and urgent health needs of the populations, and (ii) the risk of re-emergence of Ebola in the community (UNICEF 2016).

On the positive side, Ebola outbreaks have generated new networks of people and strengthened old ones, and created systems of cooperation that can be reactivated for other emergencies. Similarly, the lessons learnt in communities about epidemic response will make them more resilient to other outbreaks.

Learning from previous outbreaks: At the onset of the West African outbreak, response organisations did not initially draw on previous experiences in Ebola outbreaks in Africa, such as the work of Hewlett and Hewlett (Hewlett and Amola 2003, Hewlett and Hewlett 2008, Hewlett 2016) and Epelboin (Epelboin and Formenty 2011, Epelboin, Odugleh-Kolev et al. 2014). As an example, the problems of opaque isolation units and lack of information systems, and the distrust they generated, had already been emerged in previous outbreaks, yet these mistakes were repeated in West Africa. The rotation of expatriate health staff and limited institutional capacity for social analysis within key institutions helps to explain why lessons were not carried forward. Just the sheer numbers of humanitarian and health staff that were involved in Ebola for the first time in West Africa made the transfer of knowledge within the response very challenging.

After the reflections and evaluations that followed the West African epidemic there is evidence of knowledge being carried over to subsequent Ebola outbreaks: community engagement, partnership with trusted leaders, safe and dignified burials, community involvement in patient isolation and care have become more mainstream, as illustrated by the recent DRC outbreak in Equateur province. Note that learning by emergency response workers in the field does not emerge from conventional lessons learned reports from previous outbreaks that do not include practical information. But rather, they emerge 'from team tacit knowledge, pedagogy, and problem solving' (Hutton 2018) and the participation of experienced staff in response teams. Facilitating these learning processes that yield practical and contextualised actions within the response is crucial, combined with lessons learnt pieces that are also contextualised and point to practical actions on the ground. Whilst social scientists are now embedded in Ebola response teams, they are not deployed early enough. It is necessary for the social science inputs to inform the early outbreak response, rather than mitigate post-facto the negative impact of decontextualized activities.

Lessons have also been learnt at a global level in terms of epidemic and pandemic preparedness and response as a result of the failures and successes of the West African crisis. This has led to a strengthening of the role of the WHO as global coordinator, the creation of a global network of social scientists mobilised for future responses, building capacity and resources of developing countries to prepare and respond to epidemics, and the reinforcement of global systems of surveillance and reporting (Moon, Sridhar et al. 2015). Challenges remain, however, in terms of political commitment and financial resources to build national surge capacities, addressing problems raised by trade bans, funding research of Ebola therapeutics, creating norms regulating the sharing of data and samples, harmonising clinical trial systems, and institutional support to WHO to enhance responsiveness and transparency (Moon, Leigh et al. 2017). The question that remains is how to ensure that lessons are indeed learnt and that reviews of past epidemics truly bridge the gap between policy and practice (Hutton 2018).

Post-emergency recommendations:

Operational

- Communication at the resolution of the epidemic must be directed at combating stigma of health workers and survivors. Community engagement should be sought to create mechanisms of reintegration into communities.

- Communities should be engaged in decommissioning on where those assets and resources will be redirected, considering the non-Ebola health needs of those communities. People should be informed of risks of Ebola re-emergence and the procedures to follow if this were to occur.

Building capacity

- In the early recovery phase, support health authorities to establish sustainable and community-based mental health and psychosocial services. These services should be built for the longer term to ensure they address the wider need. As part of ongoing health system strengthening, every health facility should have at least one person trained and a system in place to identify and provide care for people with common and severe mental health conditions.

- Survivors should receive appropriate health care tailored to their sequeale, something that requires a whole programme of activities. For the purpose of communication, it is important to question whether the identity of 'survivor' can have negative consequences for those who are defined as such by aid or health programmes.

- Establish a mental health and psychosocial support strategy for Ebola cases, survivors, contacts (particularly those in isolation), family members, and the broader community. Ensure that the strategy addresses fear, stigma, negative coping strategies (e.g. substance misuse), and other needs identified through assessment and is building on positive, community-proposed coping strategies. To assist in the care and social reintegration of survivors and their families, close collaboration is needed between communities and health and social welfare services.

- Donors should partake in the reconstruction of economies, vulnerable livelihoods and health systems affected by Ebola.

- Establish learning exchanges within aid organisations and health staff (including current staff but also previous staff involved in previous Ebola outbreaks) to promote peer-to-peer learning that is eminently practical.

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About

The Social Science in Humanitarian Action Platform (SSHAP) aims to establish networks of social scientists with regional and subject expertise to rapidly provide insight, analysis and advice, tailored to demand and in accessible forms, to better design and implement emergency responses. SSHAP is a partnership between the Institute of Development Studies (IDS), the London School of Hygiene and Tropical Medicine (LSHTM), Anthrologica and UNICEF Communication for Development (C4D).

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