

# Helpdesk Report: Ebola Regional Lesson Learning

### Date: 19 December 2014

**Query:** What are the lessons learned from previous Ebola outbreaks and the current epidemic in West Africa in relation to good practice (what has worked/not worked) for behaviour change and social mobilisation interventions for preparedness?

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#### 1. Overview

The Ebola outbreak currently affecting West Africa is the most serious trans-national medical emergency in modern times. It has the potential to become a global health crisis. Many of the countries affected already have weak health systems, which are now stretched to breaking point. The health authorities have a limited capacity to respond and in a context of widespread fear and misunderstanding about the nature of the disease and how to prevent it.

Alongside addressing human resourcing, health system and pharmaceutical challenges, social mobilisation is increasingly recognised as a key component of any strategy that aims to bring the Ebola outbreak under control. This helpdesk seeks to establish what lessons have been learnt from the current and previous Ebola outbreaks. It recommends good practice and makes suggestions based on the evidence for good practice and preparedness to reduce transmission and prevent further risk and exposure in affected countries.

The resources have been divided by country focus. The four main countries, which lessons are drawn from, in the overview are Liberia, Sierra Leone, Uganda and Nigeria. Some experience from other countries is included in the main body of report including: Guinea, Senegal and Mali. Due to the time restrictions for this report, limited analysis was completed on the differing risk and levels of exposure to Ebola experienced by different countries in the region. Further time would also be required to offer analysis of different issues relevant to urban and rural populations.

#### Lessons learnt and approaches from Liberia

Liberians are 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. This demonstrates that Liberians accept Western medicine and have a very modern and market-driven drug culture. Urban areas offer access to drug markets. Local drug vendors are likely to be the first point of contact for individuals seeking to resolve a perceived critical healthcare issue. Intervention through the marketplace to educate and network with the highly organised local and regional drug markets across Liberia are recommended (Abramowitz et al 2014 a).

Contrary to a widespread perception of "ignorance" and "lack of education", research from Liberia indicates low-income and low-resource communities can rapidly assimilate correct health information and dispel incorrect information, even in a context of heightened instability, suspicion, and misinformation. Community members can, within two weeks, demonstrate rapid social learning of correct information about the source of the Ebola virus and methods for prevention, as well as the rapid dismissal of incorrect information about the virus. A critical moment for a shift in social learning took place during days 7-10, of a total of 14 (Abramowitz et al 2014 b).

In urban Liberian settlements, social learning was the principal vehicle through which local communities learned about Ebola in the early months of the outbreak. Information was also distributed through public media, social media campaigns, and direct education initiatives. There was a quantitative shift in the acquisition, retention, and discarding of accurate and inaccurate health information about Ebola virus during the early stage of the emergency in Monrovia. There was also a qualitative shift in local populations' perceptions of the truthfulness of public health messages. As time passed, people became more persuaded by public health messages (Abramowitz et al 2014 b).

Incorrect and misleading information complicated social learning. The historical distrust of government and public health messages also damaged social learning processes. However, it was found it was possible for communities to abandon non-factual information and acquire and retain factual information, about Ebola. However, some Ebola messages were accepted, but deemed not very practicable in daily life. Two examples include apparent conflicts over contact with bodily fluids and avoiding public gatherings. Both of these issues require further investigation (Abramowitz et al 2014 b).

Conspiracy theories, fears about poisoning, or beliefs in malevolent sources of disease do not preclude social learning about Ebola prevention, care, or treatment. The presence of conspiracy theories may reflect the reasonable social response to ongoing failures to contain the epidemic, including a lack of confidence in governmental and international interventions, and a lack of confidence in a weak and overstretched health sector response (Abramowitz et al 2014 b).

The handling of dead bodies has influenced attitudes towards mass graves and seeking treatment. Many families would like direct involvement in determining the treatment of their family members' bodies. To redress these issues, it is recommended that at least one family member should be present to observe the burial or cremation. Communities are concerned about the disappearance of both sick people and corpses who had been removed by health teams and burial teams (Abramowitz & Omidian, date unknown). Family members should be informed of how their relatives had died and whether they had been buried or cremated. Photos of the body may also provide evidence. Public communications can take place daily outside of hospitals to inform which patients are receiving treatment, have been discharged, or have died (Bedford 2014 b, Abramowitz & Omidian, date unknown).

It may be important to establish whether the cause of death was actually Ebola or not. Many other conditions have similar symptoms. A protocol is needed for establishing cause of death. The protocol must be stuck to, if accusations of favouritism are to be levelled at the

authorities. The alternative is for every dead body to be burned (Abramowitz & Omidian, date unknown).

The immediate implementation of a birth and death registry can assist the authorities with dealing with Ebola deaths. Local community leaders can act as key data collectors, surveillance, and reporting. Creating a "Missing Persons" Ebola Registry with ties to hospitals, ETUs, and communities will help family members track down lost loved ones (Abramowitz & Omidian, date unknown).

Cremation was found to be acceptable on public health grounds, although there was debate about what to do with the ashes. A mass grave site for cremated ashes may help cremation be socially accepted. Alternatively ashes can be returned to family members, as proof of death or a token of remembrance (Abramowitz & Omidian, date unknown, Omidian et al. 2014). There was some concern that the ashes could still be infectious. Also, some cultural resistance to cremation may exist. This is usually centred on mourning family members having nowhere to go to remember the dead. There may also be resistance to the authorities being involved in funerary practices. To counter the resistance it is recommended the authorities communicate why cremation is necessary. Also clear instructions need to be distributed for when corpses are not collected by health or burial teams. Specific information must be passed on regarding effective cremations. Inscribing the names of the deceased on memorials or an annual day of remembrance may help. (Abramowitz & Omidian, date unknown, Bedford 2014 b). Funerary parades can be held to honour the dead. Memorialisation practices should be introduced immediately. Ashes can also be returned to family members if they require. Communities should be reassured that cremation is a temporary measure, but that no exceptions can be made while a cremation policy is in place. It may be necessary to have separate religious spaces for each religion at cremation sites. This should also be done at mass burial sites (Abramowitz & Omidian, date unknown).

Mass burials may be preferred to cremation, and can provide community members with a place to remember the dead. Alternatively mass grave for ashes can effectively serve the same function as a mass burial grave. Mass burials may impact land ownership and land tenure debates. They may also cause concern about environmental pollution. Public health messaging can provide correct information about whether or not the burial of infectious corpses and cremation results in soil, water, and air contamination. A public statement could help address concerns over land ownership. It is recommended that any sites selected for mass graves must not be currently contested property. Consultation with the appropriate land authority may be necessary. As Monrovia has a highly heterogeneous population, no one religious, ethnic, or class-driven set of practices should dominate the process of mass burial, the organization of mass burial spaces, or the processes of memorialisation (Abramowitz & Omidian, date unknown).

In terms of memorialisation and the future, the creation of a scholarship program would help to support Ebola orphans through their educations. Also, funding programs could be established to help communities support Ebola orphans feeding, clothing, and wellness through their childhoods (Abramowitz & Omidian, date unknown).

New infections of Ebola can be combated through advocacy meeting with local leaders and communities. Measures can be put in place in communities, such as watch groups and compulsory hand washing. All members of the community can help to report and monitor the situation. Everyone should be made aware of Ebola. Testimonies from Ebola survivors can increase confidence in the affected communities. Health education accompanied with distribution of hygiene kits and demonstration on hand washing. Youth and women's groups in particular can assist with the mobilisation of these measures. Religious groups can also improve sensitisation (Partners meeting 2014).

The experience of youth groups should be built on. Many youth groups were active prior to the outbreak. The positive platforms and previous engagement activities should be developed as part of the social mobilisation effort. The energy of youth groups needs to be harnessed in a positive and strategic fashion. Ensuring youth groups have a single spokesperson who works directly with the elders will allow for easy flow of information. Positive engagement with supportive supervision is essential to structure youth activities and mitigate the risks associated with disenfranchised youth. Acquiring transferable skills will build capacity for the future and may help address the inevitable vacuum that will be left when Ebola crises is under control (Bedford 2014 a).

Adequate community engagement is key in the overall response. Denial, fear, panic, traditional practices and running away of contacts contributed to the exponential increase of cases and deaths. A quick response is essential. Counties with weak capacities should be assisted robustly from onset of the outbreak.

Community involvement and support to local authorities should be sustained until the situation improves in the affected neighboring counties (Partners meeting 2014).

While further research is needed, data from Liberia indicates the number of Ebola cases are in decline. It is suggested this may be in part due to door to door screening by community teams that know each individual are looking for early identification of those with fever for isolation during the critical 72 hour period after symptoms begin to prevent contact and transmission. Public awareness prevent transmissions. High population density and contact rates present significant challenges for screening and isolation in urban areas (Bar-Yam 2014).

Communities can draw upon survivors as resources in the outbreak. This may reduce fear and stigma towards Ebola victims and survivors. Psychosocial support may need to be offered by the community to those who have been affected. Communities will need guidance for how to proceed with a sick individual when they are turned away from hospitals, for building and supporting holding units in communities, and for reporting deaths when their calls to hotlines go unanswered. Community leaders may have a responsibility for individuals' health. As such, interventions involving surveillance and monitoring will need to involve their input. Identification numbers would allow every death to be counted (Abramowitz et al. Date unknown).

Communities should be equipped with the material and knowledge resources to help build a surveillance infrastructure that can inform a stronger post-epidemic state architecture. Medical infrastructure and professional surveillance mechanisms must be prioritised at the same time. Surveillance delivered by communities may result in violence or remilitarisation of disenfranchised youth communities. In the short term the shifting of surveillance responsibilities to highly structured hierarchies within local communities can also politicize micro-networks of communities. That risk can be moderated by ensuring that required resources are supplied and are not the subject of competition within and between groups (Abramowitz et al. Date unknown).

In Liberia it is important to consider that people's war experiences affect how people react to government messages. Trust in government messages may be lacking. When someone dies of Ebola, it is common for survivors to pack up and move to another area. This may make tracking difficult and may contribute to the spread of the disease. There is critical need for health services, but also need to care for those traumatised or displaced. In addition provision of food, shelter and livelihood may be required. There should be at least one trained person in every community to educate people on key Ebola signs and what to do if someone is sick. This could be a village health worker who is already trusted. Messages must be kept simple and few in number. Local spokespersons should be trained to answer questions that may arise. It is important to address their fears. Information on what to do and why you should do

it is needed. If people are not told why, they are less likely to follow instructions (Omidian et al. 2014).

It is recommended that at least one health and burial team in each district and more than one ambulance per county. Existing health care facilities across the country should remain open to deal with other illnesses, diseases and accidental injuries. More Ebola Treatment Units and Holding Centres across the country are needed. Where possible, Ebola Treatment Units should be made child friendly. Every health care worker should be aware that every patient is a potential Ebola patient. They should have training and use of PPEs, with a strengthening on universal precautions (Omidian et al. 2014).

Re-enact ceremonies were used during the war by relatives who did not have been a body to mourn. Rituals to commemorate the dead may assist families grieving for a relative who has died of Ebola. Positive action is encouraged to give people something to do. Without something to do, people may react badly (Omidian et al. 2014).

A practice described as false burial is reported to be carried out in some areas of Liberia, which involves the body being kept above ground for quite a while after death. This practice and its impact needs further investigation (Bedford 2014 b).

#### Lessons and approaches from Sierra Leone

A study of public attitudes in Sierra Leone (UNICEF, FOCUS 1000 and CRS 2014) identified radio to be the preferred means for receiving information about Ebola "by far". House visits by health professionals is the second most preferred. Television is more preferred in urban settings such as Western Area and Bo Town as compared to rural parts of the country. Health professionals and Government/MOH was found to be the most trusted source of information. Health professionals are least trusted in Western urban areas.

A group of INGOs under the Start fund produced radio jingles, posters, fact sheets, banners, newspaper ads, and motorcade air jingles for indirect sensitisation of communities (Start Fund 2014). Direct sensitisation activities: door-to-door campaigns and organising community meetings to discuss the disease went further in appeasing fears and providing clarity about the causes of the epidemic and how to control it. Analysis of the impact indicate that there was a clear increase in the awareness of Ebola and how it is transmitted and prevented. Anecdotally, the Start Fund projects did observe some specific short-term changes, such as lower attendance at funerals, increase in hand washing and using gloves, decrease in hand shaking and increase in precautions from frontline health workers when caring for patients.

The Social Mobilisation Action Consortium (SMAC) had success with triggering/supporting community mobilisers and radio broadcasting (SMAC Situational Report: 01/12/14-07/12/14). Members of the NERC Media Group were impressed with SMAC's approach in training and supporting partner stations to produce local programmes that meet the needs of local audiences and how it's bringing out stories of change and impact from the community through coordination with other consortium members.

ACF have designed and piloted the "Community Led Ebola Management and Eradication" (CLEME) approach in Moyamba District (ACF International 2014). This approach responds to the deeper need of social mobilisation to trigger behavioral change in order to strengthen community resilience to EVD outbreak. The CLEME approach provides the communities with the tools to identify their unsafe practices that could lead to potential EVD infections and to identify solutions that fit the individual and community's needs, culture and available resources. Initial results of the CLEME approach are encouraging. Following the triggering most of the communities immediately decided to take actions to address the identified risks designing their own Ebola community action plan. Communities have established hand

washing facilities, community support groups, volunteer support, isolation units, and by-laws for prevention.

Oxfam's response has been a community-centred social mobilisation module which starts with forming committees in the community and includes all organisations involved in outreach in the area (EC 2014). Members of these committees are being trained to be the link between the service providers and the coordination mechanisms and their own communities. It is essential that committee members are selected by their communities. Currently, 700 committees have been trained in Freetown and Port Loko and although it is early days, positive feedback has been received on Community Care Centres (CCCs). People prefer playing a role in the response rather than waiting for an outside intervention. Each community produces an action plan with a "barrier analysis": what stops them complying with all the advice offered by the national coordination mechanisms? Information, misinformation, cultural practices, transport issues, communication are part of a whole range of issues preventing people from being rapidly referred. Whenever a person is referred however information should flow back to the family about the patient.

Research with communities in Kailahun, Kenema and Koinadugu suggests (King 2014):

- Compensatory burial practices might address obligations for contact with the dead
- Emphasizing the material benefits of testing and quarantine centers can enhance uptake
- By-laws are being employed as instruments of behavioral change
- Sexual intercourse by survivors may be contributing to transmission

# Lessons and approaches from Uganda

Understanding local views and responses to an outbreak is essential. Although some cultural practices in Uganda, such as burial practices, were found to amplified the outbreak, most people were willing to modify and work with national and international healthcare workers to reduce its burden (Hewlett & Amola 2003). Interventions undertaken in Uganda to combat Ebola included partnerships with communities, community based disease surveillance, media work, developing diagnosis and tracking technology, improving infection control and hospital waste management, and focusing on the legal, ethical and social issues that emerged from the outbreak. These interventions were promoted and delivered as a result of national and international collaborations (Ssali 2014).

Building and holding public trust was regarded as a key component of the battle against Ebola in Uganda. Ebola evokes fear and apprehension at individual and community levels. Intensive communication with the public is needed to counter this. Press epidemic status reports should be delivered several times a day. The media must be on board to achieve the trust of the people (Omaswa 2014).

National hotlines can provide information to the general public 24 hours a day. In addition, information can be provided by community or village leaders, as they work alongside health teams. In Uganda, Ministry officials moved to live in the affected districts. Ministers and officials travelled to villages to address the public and inspire local health workers. Technology must be used to its full potential both in terms of diagnosis and reporting. International partners can supply the technology, but progress can only be made where there is effective local leadership that is trusted by the local population. The Ebola outbreak in Uganda was controlled through strong primary health-care principles, including leadership from the top, integrated with routine governance of society and involving the active participation of the people themselves (Omaswa 2014).

The rapid formation of coordination committees was also part of the successful action taken in Uganda. The Government's role in coordination of both local and international support was

vital. In the absence of reliable information made available to the public, rumours can start (Okware et al. 2002) Any strategy to stop Ebola must prevent excessive fear, which, it is expected, would reduce stigma and other negative outcomes. The provision of public information is vital. The authorities with information about the outbreak must be open and honest about the situation (Kinsman 2012). Thus, rumours and misconceptions can be addressed by frank and open discussion of the epidemic, providing daily updates, fact sheets and press releases. Information must be regularly disseminated to communities through mass media and press conferences. In some instances, controlling Ebola brought fractured communities together to battle the common problem (Okware et al. 2002).

### Lessons and approaches from Nigeria

Educating the public about Ebola transmission and prevention is a critical part of efforts to contain the outbreak. Information on Ebola has been successfully provided by UNICEF through social mobilisation efforts, including outreach teams going door-to-door and organising public gatherings (Moser 2014). Also, UNICEF's text message platform has been credited as a successful intervention in preventing the spread of Ebola in Nigeria. The accuracy of the information provided is believed to be critical to its success. The responses and replies being in real time also helps. The information provided was successfully cascaded through the community by people sharing the information (Njoku 2014).

As soon as Ebola reached Nigeria, an Emergency Operations Centre (EOC) was established. Communications and data sharing between urban areas helped to contain the outbreak. Being prepared can help develop a coordinated and effective response, should a future outbreak occur (Shuaib et al 2014).

# 2. Material on the West African region

# Minutes of the Ebola TF meeting of 28/11/2014

European Commission. Directorate-General Humanitarian and Civil Protection– ECHO (Not available online)

In Sierra Leone and Liberia, Oxfam has run projects for over 20 years, during the war and the recovery phase, especially on WASH but always with a social mobilisation dimension. One of the key challenges has been the recruitment of human resources as reported by the latest UNMEER Sitrep (shortage of over 20 000 community volunteers who are necessary to do door-to-door mobilisation). Another challenge lies in coordination. It is difficult to see who is doing what but communities have to be active in the decision-making. In Sierra Leone more district-level coordination is needed (at least 400 skilled coordinators are missing) in addition to proper transport and communication systems.

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In general, could be summarised as follows: In Sierra Leone the needs regarding sensitisation and social mobilisation are mainly for skilled coordinators to be embedded at sub-national level and more resources for social mobilisation, whereas in Liberia what is needed is more communication, ambulances and even helicopters for rapid transfers from remote areas.

IRC welcomed the fact that sensitisation and prevention was on the agenda. Communities should understand the epidemic and be active partners in the decision-making. They must lead activities and know how to respond to new infections. Funding mechanisms should be transparent. In Lofa, efforts to integrate community engagement into surveillance led to less than 1% loss of contact follow-up. Regarding safe burials IRC said that communities will not change their practices if they do not have clear alternatives. Traditional practices must therefore be understood in order to engage with communities. If people continue being afraid of the disease it is less likely they will report the symptoms, which is why IRC is also working with psychologists and anthropologists. The response should support the communities with culturally appropriate medical options to respond.

ECHO noted that sensitisation has been considered important from the beginning but it is not always obvious to donors how much of the sensitisation activities a partner covers and whether the coverage is universal or whether there are still gaps. It is also difficult to see the overall picture as for example UNICEF sub-contracts activities. The other issue is the estimation of training costs and all activities related to sensitisation. From a donor perspective there is a need to get more clarity and understanding on these issues. UNICEF and Oxfam acknowledged this reality but also said their sensitisation activities have been underfunded. UNICEF has engaged with other partners (in the spirit of the transformative agenda) but did realise things are not working well enough, in this specific crisis, and is therefore doing more alone.

On the resistance among the population in certain parts of Guinea, UNICEF said their staff is aware of this and was working on it.

On the issue of integrating survivors in the response strategy, UNICEF and Oxfam agreed these persons can make an important contribution by telling their story of how they have gone through the disease. Ways of using survivors should be increasingly explored although when it comes to medical interventions, ECHO also explained there is no complete certainty yet about the type of immunity survivors benefit from. Anybody working with infected patients therefore still works in full PPE.

The AAA/Wenner-Gren. Ebola Emergency Response Workshop. November 6-7, 2014 http://f-origin.hypotheses.org/wp-content/blogs.dir/2225/files/2014/11/Workshop-Preliminary-Guidances-and-Recommendations.pdf

In recent months, under the phrase "Everything is now Ebola," communities have become more cautious about disregarding signs of illness, but the culture of health and the culture of medicine as it is practiced in local communities significantly informs the process of domestic concern, domestic diagnosis, triage, and subsequent healthcare seeking behaviours. These local cultures significantly inform decisions about self-reporting, peer reporting, and quarantine.

 Health care messages and requirements need to be refocused to address the multigenerational interdependence of Liberian households. To date, communications that address health care provision among local populations have advised avoiding contact with people who are sick, avoiding the sharing of toilet facilities, exposure to bodily fluids, and overall isolation. This strategy is not viable for most of the population, who are either involved in direct physical care for the very young (under 12) and the very old (over 40). It is unlikely that families will abandon family members who are unable to care for themselves, especially if doing so imperils the lives of the young, elderly, and handicapped who are vulnerable without their care

- Trust local communities to experiment and innovate, and to generate a variety of local and borrowed solutions. Support them in this process. Local populations are learning about treating Ebola rapidly, through trial and error. These processes need to be closely monitored and supported, and studied for healthcare innovations. For example, in Liberia, people are adopting a strict no-contact policy. Some are putting plastic on their house for protection.
- The situation is highly fluid. There was resistance to homecare in Sierra Leone, only wanting hospital care. Then they changed their mind. Solutions will need to be revisited every 2 weeks to realign with local perceptions and needs.
- The assets and gains offered by proposed community care centres (CCC's) need to be made clear. What, precisely, is the CCC supposed to do? Is it for quarantining the sick who have not been diagnosed with Ebola? Asymptomatic people who have been exposed to Ebola? Or is it meant to be a transit unit between the community and the hospital?
- Community-based care support models should be seen as complements to, rather than competitors with, hospital-based care.
- Immediately implement an active and ongoing research program on the social factors involving care-giving, care-seeking, and healthcare provision. We need more research regarding social factors, care practices and outcomes.
- We need to provide better support for caregivers, from household caregivers, to caregivers in clinics and in hospitals. Home health care kits, including ORS, rehydration powder, fever medications, thermometers, soap, and a cell phone and radio can help individuals make decisions about care.
- Immediately implement an active and ongoing research program on the social factors involving care-giving, care-seeking, and healthcare provision. We need more research regarding social factors, care practices and outcomes.
- Practical guidance need to be widely disseminated about the fact that Ebola continues to be present in sperm for 90 days following Ebola. Based upon HIV/AIDS experience, it is unlikely that basic communications messaging practices will prove effective in addressing this issue. Instead, direct community engagement around issues of infection and sexuality is necessary. Abstinence-only, or condom-recommendation messaging will not be effective in the absence of a grassroots engagement with issues of prevention, sexual behaviours, and response. This must be undertaken carefully, as this is a critical area for the emergence of stigma and social isolation.
- Presently, survivors are being regarded as a "human resource asset" rather than as fragile individuals who have recently been extremely sick. Health interventions are accelerating towards institutionalising the assumption that survivors will be able and willing to continue to work on Ebola-related issues, when in fact, individual survivors may want nothing to do with Ebola ever again. Furthermore, we do not know enough about the duration of Ebola antibodies to position recent Ebola patients in a caregiving capacity.

# Communications:

 Message Content: Early messages meant to instil fear in local populations about Ebola had the effect of terrifying people and driving reports underground. Subsequent messages about "Ebola has no cure" are going to be problematic if and when we do find a vaccine. In both cases, simplicity has the effect of undermining desired behaviours and outcomes. Ebola communications messaging efforts need to take a more open approach that seeks to educate in the context of an evolving situation, and explains to local populations why and how the situation is evolving.

- Myths and Beliefs: Liberians, Guineans, and Sierra Leoneans tend to be medically pluralistic, which means that they simultaneously pursue multiple healing strategies and beliefs simultaneously, without experiencing the different domains (ex. Christian healing, biomedicine, traditional medicine) as in conflict.
- It is entirely reasonable and sensible that local populations are capable of receiving sophisticated public health messages about Ebola causes, management, and patterns of transmission as a virus while simultaneously believing in alternative explanations (Ex. Sorcery).
- Learning Curves: Health communications follow learning curves. Effective communications campaigns will notice widespread misinterpretation and misinformation in the immediate implementation of the campaign, but will rapidly observe (within weeks) a widespread correction in the population, as the message is correctly filtered and absorbed. Ineffective messaging campaigns will show no such change. Present health communications campaigns are overly concerned with immediate acceptance and learning of the prescribed message, and need to offer greater information, and have tolerance for greater initial error.
- Health communications networks should be structurally integrated into case reporting procedures.
- Best Practices:
- Work through established community leaders (not Ebola context self-appointed leaders)
- Door-to-door campaigns
- Use social networks, rumour, and "social learning"
- Use hopeful and positive messages
- Focus on empowerment
- Encourage but don't coerce survivors to talk about experiences
- Multimedia: We recommend a significant distribution of free one-way and two-way
  communications devices (transistor radios, cell-phones) to facilitate the unidirectional
  and bidirectional flow of information between local communities and response
  coordination. To date, multimedia messages have been tremendously effective in
  distributing Ebola information. The video of the Liberian nurse who provided
  homecare to her family was shared on cellphones across Monrovia, and was
  reported even further by word of mouth. Expatriate Internet radio call-in stations have
  been used to circulate Ebola-related information and messages.
- Work with all religious communities: Pentecostal and Seventh-Day Adventist populations are the fastest growing segment of Liberian and Sierra Leonean religious populations, but they have not been integrated into the Ebola response in the way that mainstream Catholic, Methodist, and Episcopal communities have.
- This is regarded as highly suspect by local populations, and discredits Ebola outreach campaigns among a growing majority of Christian populations. In Guinea, the national network of Imams is known for spreading important information and can be implicated in the Ebola response as well via the Ministry for Religious Affairs or more informal networks.
- Mixed messages: Concern about "mixing messages" has inhibited a robust Ebola response. For example, although healthcare has been managed principally at the community level, health-messaging campaigns have been hesitant to share information about how to manage homecare because responders are concerned that it will undermine the ETU and Hospital model of care. These concerns should be set aside. The Ebola response should take rapid steps to "meet people where they are," and provide information and support to caregivers where there are. Such allowance for complexity will allow more trust in the askance reception of previously seemingly incongruent information.
- Develop longer-form communications messaging outlets: Call-in radio shows, Fireside chats, radio-based trainings on home or CCC-based healthcare, Q&A internet shows, internet radio broadcasts from the diaspora

- The concept of "Home": Be advised that the concept of home does not mean the same thing in West Africa that it mans in Europe or the United States. When people hear "stay in your home" in Sierra Leone, for example, they may think to themselves, "oh, I'll just go home to my grandmother's house in the village to wait out the lockdown." Home means, "Where are your people from," as well as "where do you live." And given the wide degree of cultural heterogeneity, most people have many homes.
- Overly Simplistic Messages: Evidence suggests that local communities have rapidly learned and mastered a core set of messages about Ebola transmission, management, and treatment strategies, and that communities are not dealing with a lack of basic information, they are trying to manage Ebola with a lack of sophisticated, detailed, and relevant information (ex. How to clean up Ebola-infected fluids in a household with a cement or dirt floor; how to safely perform a burial when burial teams do not arrive; How to provide resources to quarantined individuals and families under complex conditions. Community messages need to become more sophisticated, more relevant, and more detailed, but must also integrate local conceptions of disease and misfortune (ex. "Swears" - SL).
- Photojournalism: We recommend the exercise of far greater restraint in the
  photojournalism campaigns deployed in this epidemic, for both fundraising and
  reporting purposes. Current photojournalistic representations of sick and dying
  Liberians, Guineans, and Sierra Leoneans are uncompassionate and inhumane.
  Individuals who are suffering, in extreme pain, and are writhing on the ground fighting
  for their life are not being granted their dignity when their images are splashed on the
  cover of major news mediums, websites, and fundraising material. Such images are
  also contributing to the perception that all Africans are carriers of disease, and are
  creating a hostile and discriminatory environment for African expatriates globally.
- Avoid "war" imagery: While fighting, attack defence, and war are all powerful images for mobilization, the application of war imagery to the fight against Ebola can have the effect of supporting social conflicts, sedimenting social divisions, and making people feel like they have to physically mobilize or flee.
- Remember your audience. Perhaps shift to a soccer metaphor instead?
- Ebola as Political Critique: Communications around Ebola messages can (and have been, in the past (Gabon) been effectively to attack national governments, with the consequence of delegitimising the Ebola response. Backstage political interventions may be required to prevent or divert this kind of action. When deployed by diaspora communities, it can discredit Ebola-related messages that are concurrently offered.
- Emphasis on "care," not on "war": The focus on war imagery may lead to distorting effects downstream. It is imperative to focus on widely resonant conceptions of caregiving and responsibility, rather than on resistance and battle. This will become particularly important if and when blood plasma transfusions are adopted widely for treatment of Ebola patients. The "gift" of blood will be more gracefully acceded to than the demand for blood to fight a battle, which has negative resonance with how occult conceptions interacted with the practice of war.

# Attending the dead:

- As in the context of other Ebola crises, the local community has received the public health message that corpses are a potential source of transmission of Ebola. While this message may need to be extended further into rural communities, the next path of communication needs to address the specific needs of local communities for the management of dead bodies, especially in contexts in which it may not ever be known if individuals have died of Ebola.
- Guidance regarding burials needs to accommodate the fact that requesting the assistance of healthcare teams or burial teams is unpractical in many contexts. Alternative guidance need to be shared, and an ongoing open forum needs to be

created for local communities to engage in specific questions and answers with local experts.

- It is unlikely that the Ebola response will be able to identify a "one size fits all safe burial" set of practices.
- Instead, core recommendations should be made that can be integrated into diverse ethnic, religious, and regional communities.
- Family members want a way to see the body after death. Options include photographs, cell-phone photographs, and personal witnesses. This will alleviate concerns about bodies disappearing, and address fears that family members' bodies are being used for ritual mutilation and dismemberment.
- Communities and families need a more complete explanation of what is happening to bodies after death. Transparency and visibility is key to resolving existing distrust issues.
- The location of buried bodies or cremated bodies needs to be made widely known and highly public.
- There is considerable religious diversity within families, and burial practices need to address the religious requirements of the deceased. This cannot be inferred from the religion of close contacts or relatives.
- Local communities are innovating alternative burial practices, and have historically done so, as well. For example, once West Africans began migrating abroad, it was not possible to convey the body to a home village for burials. Alternative practices were implemented that involved practices like touching a stone or wood to the skin of a corpse, and sending the stone or wood home. Communities that have innovated new practices should be credited for having done so in public campaigns to replicate these practices elsewhere, as this is a mark of prestige and local legitimacy, and can function as a community-based endorsement of the practice.
- Sylvain Landry Faye has considerable experience working with local communities in Guinea to adapt funerary practices to the Ebola context. His efforts should be scaled up and circulated widely.
- A national day of memorialisation should be created in countries where local communities desire it.
- Furthermore, resources should be made available to support local communities in existing days of mourning, as with the annual "Cleaning the Graves" day in Liberia, forthcoming in Spring 2015.

Identification and diagnosis in local communities:

- Local communities should assume responsibility for surveillance. Local community leaders can serve as a two-way communication source for the transmission of needs, concerns, problems, and innovations in the community, and the reporting of cases of infection and death to health authorities.
- At the community-level, previous systems implemented under governmental authority can serve as a template for community surveillance and identification. For example, in Guinea in the 1960's-1980's, every community had a local dispensary, and the manager of the local dispensary kept track of the health status of individuals in the community on a daily/weekly basis. If any individual showed signs of unusual or atypical symptoms, the dispensary would note the fact that someone was sick on a chalkboard or in a notebook, and the information would be sent to sub-regional health offices, which would respond with further investigation and treatment protocols. This is a system that can be implemented.
- Heightened community-level surveillance in the absence of careful community guidelines for doing so can result in negative consequences. Increased reporting might lead to an increase in locals concealing contact with someone who has had Ebola, or deferring informing someone about symptoms of illness, out of a fear of shunning or being reported.

- Heightened community-level surveillance can also lead to scapegoating. Perceptions
  that someone has Ebola can result in the scapegoating of individuals in the
  community who have moved in or arrived from outside the community or from other
  countries; as well as marginalised individuals, and individuals who appear to be
  symptomatic or sick for any reason. This can result in the loss of jobs, sources of
  revenue, and isolation as well as mob violence towards specific individuals.
- If the consequences of reporting are seen as excessively punitive, fearsome, or disrespectful (see Sierra Leone model vs. Mali model) community members can revolt, or undermine local authorities.
- Community-based trust must be supported at all times. Local leaders must be able to retain their role as legitimate stewards, allies, and representatives of their local communities, and not seem to be allied state or the international community against the local community.

# Communication with rebellious communities during an outbreak of Ebola Virus Disease in Guinea: an anthropological approach

Anoko J. 2014 <u>http://www.ebola-anthropology.net/wp-content/uploads/2014/12/Communicationduring-an-</u> outbreak-of-Ebola-Virus-Disease-with-rebellious-communities-in-Guinea.pdf

This paper reports on the success of a communication programme among 26 rebellious villages in Forest Guinea during fieldwork in June-July 2014. This was based on listening to complaints and taking into account the customs and culture of those concerned. The main methodologies were socio-anthropological enquiry and action research, based on bibliographic research, observations, formal and informal interviews with resource persons and political leaders from Forest Guinea; women, young and very old people of both sexes, street vendors, restaurateurs, local personal response.

In Forest Guinea just as elsewhere in Ebola outbreaks, different types of explanatory models of the illness coexist and clash: on one side, a biomedical model and protocols restricting individual freedoms and imposing draconian management measures on the sick and the dead, and on the other cultural models that attribute the disease to a trial, or a divine will, to a fault or fracture in the social order, to the ill effects of the jealous, to evil wizards and cannibalistic sorcerers, and to attacks by nonhuman spirits as jinn, the Mamiwata the "devils", the ancestors, the "rebound of fetishes" to conspiracy theories, to negationist theories including political models that attribute the spread of the virus to the criminal will of international genocide.

The coexistence of these competing explanatory models generates misunderstandings on both sides, leading to reluctance and sometimes violent resistance and various intensities as was the case in Forest Guinea, Liberia and Sierra Leone, but also in previous epidemics.

This paper reports the successful experience of mobilisation and sensitisation based on listening to complaints and taking into account the customs and culture of the peoples during the research period.

But it is a job that would be ephemeral if it is not constantly renewed alongside the spread of the virus in each new village, family, community concerned. Nothing should ever be taken for granted. Beyond local specificities, the outbreak of epidemic disasters has always raised and still raises terror and corollary psychosocial phenomena, denial, rebellion against the powers that be, the negationist theses, conspiracy theories, stigmatisation of agencies addressing the epidemic and survivors, and the search for scapegoats.

Since this successful experience, the epidemic has reached new communities that one has failed to sensitise and mobilizs adequately as verbal threats and physical violence have continued to be exerted against the intervention teams. A climax was reached in September 2014 in the village of Womey (N'Zérékoré), where eight of outreach team consisting of national administrative and medical cadres were killed by rampaging youth, supported by women.

It seems that listening and the integration as much as possible of the grievances and customs of the population often continue to be forgotten, crushed by authoritarian reflexes, urgency and the multiplicity of tasks to be performed.

# The pivotal role of faith leaders in the ebola virus disease outbreak in west Africa CAFOD. 2014. Policy Briefing Paper

http://www.cafod.org.uk/content/download/21487/149541/file/CAFOD%20Ebola%20Faith%20 leaders%20policy%20paper%20111114%20(2).pdf

CAFOD recognises that in the current humanitarian emergency prioritisation should be given to the three key pillars of treatment and isolation of suspected and confirmed EVD cases; safe burial, and prevention of the further spread of the disease through community sensitisation and contact tracing. Beyond these priorities there is growing evidence of some devastating impacts of the epidemic which also need to be addressed so that affected communities, and particularly those directly affected by the disease, can live with dignity. CAFOD's partners and staff in affected countries are reporting increasing issues of fear, stigma and misunderstanding surrounding the epidemic.

Policy Recommendations on the role of faith leaders:

- Recognised faith leaders from across the religions must have representation at high level discussions and planning on the response and they must have a voice in decision-making. There is a need to ensure faith perspectives and the reality of working in a faith context is fully taken into consideration.
- Faith leaders can make particularly important contributions in relation to safe burials and the need for changes in funeral and burial practices and in relation to sensitisation and prevention messages. Their central role in this must be acknowledged.
- Faith-based organisations and faith leaders need designated funding in order to increase the effectiveness and reach of their work in combating the spread of EVD.

Key points from the paper include:

- Faith Leaders are trusted within their communities.
- Inter-religious groups already have a track record of successfully addressing health challenges (e.g. child immunisation in Sierra Leone).
- Women play an important role in faith leadership.
- Influence of Faith Communications (in particular, church radio).
- Weekly religious services are a key opportunity for transmitting sensitisation messages.
- Importance of getting it right any messages must be factually correct.
- Many faith communities have long experience in dealing with stigma and exclusion.
- Faith-based organisations need adequate funding.
- Faith leaders can have a significant multiplier impact.
- Investing in the role of faith leaders can be good value for money.

#### Ebola in West Africa

# Maplecroft. 2014. Ebola Risk Report

http://maplecroft.com/portfolio/new-analysis/2014/11/07/ebola-threatens-regional-businesscontinuity-updated-report/

With almost 5,000 deaths and tens of thousands of cases expected before the end of the year, Ebola is having a devastating effect in West Africa. The current outbreak has now reached a decisive stage in Guinea, Liberia and Sierra Leone, with the number of new cases threatening to overwhelm public health infrastructure. Moreover, there are growing risks that the virus will spread more widely in Africa and around the world.

This risk report provides in-depth forecasting and analysis to help businesses understand how the Ebola virus could affect their operations. The report identifies the transport routes along which Ebola could proliferate, using innovative mapping techniques to display the key air and land corridors through which the disease may spread across Africa and beyond. The report provides detailed analysis of the capacity of countries to contain any outbreaks of Ebola that occur within their territory, focusing on key growth markets in Africa and around the world.

#### Case study – Sierra Leone

Sierra Leone's three-day curfew failed to contain EVD. The government imposed a three-day lockdown between19 and 21 September 2014, during which all movement was restricted in the country. Some 30,000 volunteers went door-to-door to identify individuals infected by EVD, distribute soap and inform the population about the disease. The authorities decided to adopt this measure because of widespread reluctance to seek medical assistance for EVD. During the lockdown, 130 new cases of EVD were identified and about 100 bodies of people suspected to have died of EVD were retrieved and buried. The immediate burial of highly contagious bodies of EVD victims is essential to contain the disease. Some feared that the curfew would further damage public trust in healthcare workers and government officials.

However, the public was broadly compliant and cooperated with the authorities. The lockdown also helped to reveal the deficiencies of the country's capabilities to fight Ebola, including the shortage of ambulances, healthcare workers and isolations wards. As a result, the government considered the curfew a success. Nevertheless, the lockdown did not prevent further spread of the disease. Indeed, shortly after the curfew was lifted, Save the Children reported that the EVD was spreading across the country at a terrifying rate.

# Information campaigns will likely help to limit the spread of EVD

For lack of experience with EVD, people in West Africa are ignorant about the disease's symptoms and causes, indicating a great need for information campaigns. For instance, Sierra Leone's government published a fact sheet as part of its awareness campaign which discards some of the most prevalent superstitious beliefs about the EVD. These include the belief that drinking alcohol protects against infection or that EVD can be cured by a mixture of ginger, honey, garlic, onion and vinegar. These beliefs have hampered the efforts by healthcare workers to contain the outbreak. An effective awareness campaign would require additional funding in order to reach people across the affected countries, particularly in rural and isolated communities. Moreover, without a drastic improvement in the ability of healthcare systems to provide EVD patients with quality care, patients and their families are likely to continue to rely on spurious treatments instead.

Cuba has committed one of the largest foreign medical teams coming from a single country. Alongside other medical staff, Cuba is sending five social mobilisation officers to Sierra Leone.

# The significance of death, funerals and the after-life in Ebola-hit Sierra Leone, Guinea and Liberia: Anthropological insights into infection and social resistance Fairhead J. 2014. Draft.

http://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/4727/FairheadEbolaFuneral s8Oct.docx?sequence=1

The aim of this briefing paper is to consider the various ways in which widely reported fear and resistance to the Ebola response can be understood, and what each way of understanding offers to those battling with the current epidemic. As far as this paper is concerned, there is no single 'right way' to comprehend resistance to educators, medics and burial teams, as this is a very complex social phenomenon. The aim instead is to outline the variety of ways in which resistance can be (has been) conceived and what each might suggest for better communication and response. The paper couches these different modes of understanding within a wide repertoire of perspectives that social theorists take to understanding social phenomena, as this provides an analytical framework that is as encompassing as possible.

# Ebola in West Africa: Combating Both Virus and Myths

Aldrich S. 2014. U.S. Department of State

The Ebola outbreak has changed the landscape in West Africa, especially for Guinea and its already beleaguered health system. Guineans in focus groups talk a great deal about the disease—acknowledging that myths are as widespread as facts. Misinformation is a roadblock to prevention, treatment, and recovery. But these Guineans' own words suggest innovative ways to curb the spread of both bad information and the Ebola virus itself. In focus groups, Guineans indicated ways to improve public awareness campaigns:

- Show that Ebola is not a death sentence by explaining treatment options and the possibility of survival.
- Use survivors' testimony to bolster trust in health care providers and encourage citizens to seek treatment.
- Sing the same tune. Imams, community leaders, international organisations, government officials need to be on the same page with unified and accurate messages, using local languages.
- Show, don't just talk. Include live demonstrations during public health campaigns. People learn by watching and will trust using the same bleach, soap, and sanitiser that officials use.
- (Re)Build trust. Guineans say Conakry's (and the international community's) response to Ebola was too slow. A "spirt of patriotism" is needed to help the fight.
- Ask what you can do for your country... Mobilise Guinea's large youth population to promote health campaigns, distribute supplies, and teach best practices.

# Combating Ebola in West Africa: The International Response

Shah R. 2014. Testimony of Dr Rajiv Shah, USAID Administrator, Before The House Committee on Foreign Affairs

http://iipdigital.usembassy.gov/st/english/texttrans/2014/11/20141114310879.html#axzz3MG DdcGrO

The United States has mounted an aggressive effort governed by four key pillars to stop this crisis: control the epidemic; mitigate second-order impacts, including blunting the economic, social, and political tolls; coordinate the U.S. and broader global response; and fortify global health security infrastructure.

In Liberia, encouraging progress is being made in highly affected areas, while new cases are emerging in harder-to-reach areas. The rapid scale-up of burial teams across the country— combined with a significant investment in risk-reduction strategies, including changes in traditional burial practices—has contributed to this reduction in transmission.

USAID will continue to adapt their strategy in Liberia to rapidly address these hard-to-reach cases and remain highly vigilant to further outbreaks. They are advancing the Government of Liberia's fight against Ebola by supporting the medical and non-medical management of Ebola Treatment Units; constructing Community Care Centres; supporting logistics and supply for the international response effort; ensuring nationwide access to safe burials; expanding the mobilisation and provisioning of health care workers and supporting widespread community mobilisation and information campaigns.

In Sierra Leone, the United Kingdom has surged their response in recent weeks by building on the U.S. model and the lessons we learned in Liberia, including focusing on early gains through burial teams and social mobilisations. With robust engagement from the U.S., the United Kingdom leads international efforts to implement the government's national strategy to construct Ebola Treatment Units, build Community Care Centres, and scale up burial teams. Through our partners, USAID are helping strengthen the early identification of suspected cases and contacts to break the chain of viral transmission.

In Guinea, which is roughly three times the population and economic size of Liberia, USAID have expanded their Disaster Assistance Response Team to meet increasing needs and ensure the effective coordination of aid. Guinea's Forest Region remains the epicentre of the outbreak in that country and continues to pose risks of spread to other parts of Guinea and to neighbouring countries. They are supporting the scale-up of critical interventions, including contact tracing, community mobilisation, and support for Ebola Treatment Units. This package of interventions will make a substantial difference in Guinea, as we have seen demonstrated in Liberia.

# Community listeners' clubs on the frontline to stop the spread of the Ebola Virus Disease

FAO. 2014.

http://www.fao.org/emergencies/fao-in-action/stories/stories-detail/en/c/264264/

FAO participated in social mobilisation efforts through its networks of Farmer Field Schools and Dimitra community listeners' clubs, which have been developed in the framework of several projects implemented in Senegal.

Community listeners' clubs provide a forum for the community to discuss various topics such as agriculture, environment and health. Members meet regularly to express their daily problems, make decisions and take action to solve them. "Clubs promote a sense of social responsibility and cohesion among community members, enabling them to work together for their own community", says Ibrahim Hama, communication expert for the Senegal programme.

In the department of Velingara (Kolda region), 60 km from the border with Guinea, there are 40 community listeners' clubs, in which members are regularly informed on EVD through a radio awareness campaign broadcasted by the local radio, Bamtaare Dowri.

In late September 2014, in Velingara, FAO seized the opportunity to train participants, including 40 club leaders, 10 facilitators and the director of a community radio, to address the issue of Ebola within community clubs. Four project officers, including two trainers from the Senegal River region (where the other 24 clubs are located) also attended this training.

Within the current context, all of the participants agreed to use community listeners' clubs as a key platform to create awareness among communities, although Mamadou Samba Toure, a community listeners' club facilitator in Ngoumbou (Velingara, Kolda), reminds us that the risk of EVD transmission and actions to be taken were already being discussed in the clubs. He explains for instance that systematic hand washing was initiated early on by the community listeners' clubs.

Following EVD discussions during the training, participants also agreed to involve a health expert, before or after the first club discussion, in order to facilitate community members' exchanges on this sensitive matter. Therefore, at the end of the week, the organizers of the training invited the health district chief to validate the information shared during the training.

"We have learned many things this week and the most important is that our problems can be overcome! We just need to discuss them and decide on how to address them within the community. We can solve most of our problems by ourselves!" concludes Bocar Baldé, a union technician (Velingara, Kolda).

Vincent Martin, FAO Representative in Senegal, highlights the need for this type of innovative activity to lead the response. "Such fora offer strong areas for local ownership of the messages, which are key to stop the spread of the disease. The clubs also act as a network, essential to the efficiency of early warning systems, as well as information dissemination and experience sharing. During a time of high-level risks, the clubs allow for rapid mobilization of community stakeholders regarding awareness activities."

# EU Ebola Task Force, Social mobilization

Barbara Beintein, Principal Advisor UNICEF Ebola Unit, 28 November, 2014 (Presentation) (Not available online)

The approach taken in Guinea was mobilisation of local leaders (300 Community Watch Committees - Comite de veille) and religious leaders (1000 Mosque)

Reasons for the community watch committees:

- Population felt threatened by international experts contributed to resistanceviolence
- Incomprehension: health services "kill" people
- Access to certain communities require trust building to open up village doors
- Study Johns Hopkins/UNICEF: communities more receptive when communication activities lead by their own people

# Results:

- In Kankan, positive impact of 100 Mosques now scaling up to 1,000 Mosques
- Over 600,000 households (3.2 million persons) reached with interpersonal communication
- Trained volunteers to report any person who develop symptoms In Liberia EU/UNICEF coordinated partner mobilisation; media coverage and involvement; and district level coordination.

# Results:

- Estimated 1.5 million people reached weekly
- Sub-national coordination: 30 county & 800 trained district community mobilisers
- Agreements with 50 radio stations for 1 hour of broadcast everyday

Approaches taken in Sierra Leone were: neighbourhood watch, group discussions, and doorto-door 100% coverage.

Results:

- Rapid social mobilisation response
- House to house campaigns
- Early referrals
- Motor bike rallies
- District partners engaged around community care centres
- SMS campaigns and U-REPORT

EU/UNICEF lessons learned across regions:

- Work with communities
- Triangulate information with epidemiologists, anthropologists etc.
- Hotlines in the 3 countries have helped collecting rumours and adapt strategy to respond to them
- Adapt/nuance messaging weekly as Ebola is a "moving target"
- Training of partners is essential
- Use south to south experience (DR Congo staff deployed to Guinea Conakry)

Key challenges:

- Scale up health services
- Scale up Communication/sensitisation at field level with quality staff and communities
- Updating flow of information from the field
- Keep media focus on Ebola
- Improve situation reports
- Funding needs in Guinea: 12 million euros

# In Mali, united against Ebola - a transporter's pledge

Cissé B and Ferreiro J. 2014. UNICEF website. http://www.unicef.org/infobycountry/mali\_77891.html?utm\_source=unicef\_news&utm\_mediu m=rss&utm\_campaign=rss\_link

UNICEF and the Department of Social Development have provided Ebola prevention training to 50 transport managers, who will then train union members. In addition, 140 people have been trained on water point management at all bus stations.

"With the training by UNICEF, I realised that I can protect myself against this disease and save more lives," Mr. Bagayoko (A bus terminal deputy) says. "Health is everyone's issue, rich or poor; through training, we learned the simple lifesaving skills, especially the guidelines to be observed in the presence of Ebola symptoms on people."

Alongside these trainings, UNICEF supports the Government's prevention efforts by prepositioning health supplies and tents, and acting as lead for mass communication, advocacy and social mobilisation for community-based prevention and case detection.

Following the confirmation of the first case in Mali, UNICEF and its partners have scaled up intervention activities in Bamako, as well as in at-risk areas including Kayes, Sikasso and Koulikoro regions, in an effort to keep the deadly virus from any potential spread.

"After my training, I hosted a big meeting to inform other transporters, and together we set up facilities for hand washing with soap and have chlorine on hand, particularly at points of sale,"

Mr. Bagayoko says. "No passenger goes onboard a bus without washing his hands. Thanks to the support of UNICEF, we have also displayed poster-size stickers on all public transport, buses and taxis. I want to thank UNICEF and its partners for their support, and especially the awareness for the fight against Ebola disease. We must all remain mobilized as one to defeat Ebola."

# Mobilising youth for Ebola education: Sierra Leone and Liberia

Bedford J. 2014 a. UNMEER

http://www.ebola-anthropology.net/wp-content/uploads/2014/11/Youth-mobilisatoin-keyconsiderations-Sierra-Leone-and-Liberia.pdf

This brief summarises some key considerations about mobilising youth and youth groups in the Ebola response in Sierra Leone and Liberia. It includes the following recommendations:

- Youth groups have been active in affected countries prior to the outbreak, and the response should build on their positive platforms and previous engagement activities as part of the social mobilisation effort.
- It is recommended that youth groups report on trends and perceptions in their community, not only provide information.
- The response should support the desire of young people to be involved with the response as a way of helping their community and their country but it needs to harness this energy in a positive and strategic fashion.
- Positive engagement with supportive supervision is essential to structure youth activities and mitigate the risks associated with disenfranchised youth. Providing transferable skills (with potential certification after training) will build capacity for the future and may help address the inevitable vacuum that will be left when Ebola crises is under control.
- Many young male interlocutors emphasise that youth need to present themselves and their involvement in a way that is respectful and enables them to be taken seriously by the older generation.
- It is recommended that mobilised youth groups have a single spokesperson who works directly with the elders in the catchment area. The youth can transform the elders into experts youth are the conduits for information and the elders are socially appropriate purveyors of such information. In this way, youth who possess good training will be seen as an investment by their elders.

# 3. Experience from Liberia

Preliminary Report: Community-based Reports of Co-morbidity, Co-mortality, and Health Seeking Behaviours in Four Monrovia Communities During the West African Ebola Epidemic

Abramowitz S, Kristen McLean, Josephine Monger, Kodjo Tehoungue, Sarah McKune, Mosoka Fallah, Patricia Omidian. 2014 a. Grey Literature

https://www.academia.edu/9585650/Preliminary\_Report\_on\_Community-

based\_Accounts\_of\_Co-Morbidity\_Co-mortality\_and\_Health-

Seeking\_Behaviors\_in\_Four\_Monrovia\_Communities\_During\_the\_West\_African\_Ebola\_Epid emic

In short, 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. This data has substantial implications because it demonstrates beyond a doubt that Liberians accept Western medicine, especially pharmaceuticals. Liberians have a very modern and market-driven drug culture, and there

attitude towards pharmaceutical consumption is not just accepting, it is aggressively capitalized. The long list of pharmaceuticals purchased by our respondents shows that Liberians living in urban areas and in urban and rural peripheries like Fendell have a high level of access to drug markets through market vendors, local pharmacies, and petty traders. Furthermore, local drug vendors are likely to be the first point of contact for individuals seeking to resolve a perceived critical healthcare issue.

The implications of this from an Ebola intervention perspective are important, because it suggests that an aggressive investment of resources to educate healthcare workers in local clinics and hospitals or traditional healers may carry less weight than an intervention through the marketplace to educate and network with the highly organised local and regional drug markets across Liberia.

Fear of hospitals: A small subset of twenty respondents who had a sick person in their household related that they or their family member was afraid to go to the hospital.

The Opposite of Denial: Social Learning at the Onset of the Ebola Emergency in Liberia Abramowitz, SA. Et al. 2014. Grey literature. (Not available online)

The objective of this study was to identify the pace of Ebola-related social learning in urban and peri-urban areas around Monrovia, Liberia during August 2014, the onset of the emergency phase of the epidemic. Research teams collected data in 13 discrete neighbourhood sites over fourteen consecutive days via focus groups, community discussions, and key informant interviews for the purpose of program development. Data was de-identified and shared with research partners for analysis. The study's findings indicate that within a two-week period, community members demonstrated rapid social learning of correct information about the source of the Ebolavirus and methods for prevention, as well as the rapid dismissal of incorrect information about the virus. The data also suggest that a critical moment for a shift in social learning took place after the research midpoint, during days 7-10 (of a total of 14). The research demonstrates that under conditions of accelerating health crises, low-income and low-resource communities can rapidly assimilate correct health information and dispel incorrect information, even in a context of heightened instability, suspicion, and misinformation.

In the context of the Ebola outbreak in urban Liberian settlements, social learning was the principal vehicle through which local communities learned about Ebola in the early months of the outbreak. Secondary messages were distributed through public media (newspapers, radio public service announcements and billboards), social media campaigns (text messages, community education activities), and direct education initiatives sponsored by Government of Liberia (GOL) and UNICEF community education teams. In the early weeks of the outbreak, however, the principle mechanism for learning about Ebola was through verbal information sharing, peer-to-peer verbal and text phone communications, public and private community-based conversations, and direct observation of Ebola morbidity and mortality -- in short, social learning was the dominant mechanism by which Ebola messages were transmitted, received, and internalised by local Liberian communities.

The findings from this study demonstrate that there was a quantitative shift in the acquisition, retention, and discarding of accurate and inaccurate health information about Ebola virus during the first two weeks of the declaration of a state of emergency in Liberia's urban center, Monrovia. There was also a qualitative shift in local populations' perceptions of the truthfulness of public health messages, with local populations becoming more persuaded by public health messages at the end of the study than at the beginning of the study. Overall, while certain non-factual messages continued to be reported across the population, the communities that participated in the study showed signs of substantial social learning about

Ebola prior to receiving direct instruction from the GOL/UNICEF research and outreach team that collected the data for this study.

Unfortunately, local rumours and text messaging campaigns, and the dissemination of incorrect and misleading government and international healthcare messages complicated social learning by inculcating anxiety and relaying inaccurate information or guidance at a time of critical social learning. These issues, in combination with historical distrust of government and public health messages, muddled social learning processes. Even so, the implications of this data for the capacity of low-resource local communities to engage in rapid social learning under extreme health crises are profound. This study demonstrates that it was possible for communities to abandon non-factual Ebola information and acquire and retain factual Ebola information, even amidst the circulation of governmental and international conspiracy theories, theories about the poisoning of water and food sources, and theories about health worker complicity in the spreading of the epidemic.

There are some anomalies in the data that suggest that some Ebola messages were recognised and accepted, but ultimately deemed not very practicable in daily life. The two best examples of these anomalies are the apparent conflicts over contact with bodily fluids and messages to avoid public gatherings. Both of these issues require further investigation. These issues suggest a need for both further systematic research, and a need for thoughtful consideration in policy circles about the practicality of many Ebola-related public health messages in these communities.

The implications of these findings have profound implications for current efforts to respond to the Ebola epidemic. Contrary to a widespread perception of "ignorance," "lack of education," and lack of human resources," these communities demonstrate the capacity to uptake information regarding Ebola transmission and management rapidly and efficiently. Furthermore, while Ebola initiatives may take place in communities that continue to believe in conspiracy theories, fears about poisoning, or other malevolent sources of Ebola or other infections, this fact does not preclude social learning about Ebola prevention, care, or treatment. Instead, it might be hypothesized that the presence of conspiracy theories reflects the reasonable social response to ongoing failures to contain the epidemic -- namely, a growing fearfulness and distrust about Ebola, a lack of confidence in governmental and international interventions, and a lack of confidence in a weak and overstretched health sector response. This is consistent with social learning and health practice research that explores the relevance of locus of control and self-efficacy to health messages and health actions.

Even so, without the full cultural "buy-in" of local communities to dominant explanations about the sources of Ebola and about methods of prevention, local populations in West Africa can be taught public health and medical prevention messages, protection mechanisms, caregiving skills, case management, and case tracking rapidly, efficiently, and with substantial conviction.

# Brief on attitudes towards Ebola-related funerary practices and memorialisation in urban Liberia

Abramowitz S & Omidian P. Grey Literature. (Not available online)

# Issue 1: Evidence of Death, The Proper Treatment of the Dead, and Proper Handling of Corpses

The preeminent factor affecting both attitudes towards cremation, and attitudes towards mass graves, and even attitudes towards seeking help at hospitals and Ebola Treatment Units (ETUs) was widespread concern over the correct handling of dead bodies.

Community Recommendations:

In order to redress these issues, citizens made several recommendations. Some argued that one family member should be present to observe the burial or cremation of their loved one, as living proof that the body was handled properly, with dignity. Others argued strongly that family members should be informed if their loved ones had died and been buried or cremated. Still others recommended showing photographs of the corpses to family members, noting, "When other people have died in the past of other causes, their pictures were shown to people, but when Ebola victims are dying, their pictures aren't shown."

One additional issue factor involves the interpretive "flex" that community members are employing in making a determination about whether or not deaths are caused by Ebola. There is recognition that Ebola deaths require cremation, but that other deaths do not. However, in current conditions, there are many causes of death with symptoms similar to Ebola. Furthermore, there are nearly no testing facilities in these communities. Therefore, when community members die, communities are left responsible for making a sometimes impossible determination about the cause of death – malaria, cholera, or Ebola, for example – and this has a confusing impact upon a community's determination about what to do with its' corpses. This confusion is recognised by the community, leading one person to suggest that "government needs to put a proper mechanism in place to test dead bodies." This would have the result that "if the government tests the bodies positive then the government can cremate them - cremation is allowed." In order to eliminate any interpretive flexibility, and to avoid recent impressions of favouritism re: the granting of exceptions to permit burials for certain prominent figures in the community who had died of Ebola, others recommended that "every dead body should be burned, and the government should not pick and choose."

#### Author Recommendations:

- Distribution of international health identification numbers that can be returned to family after death
- Immediate Implementation of a Birth Registry and Death Registry, with local community leaders as key data collectors, surveillance, and reporting
- Implement recommendations of the community, including:
  - Providing photograph of corpses to family members
  - Provide written or verbal notification to family members
  - Public daily listings outside of hospitals of patients in treatment, discharged, or dead
- The creation of a "Missing Persons" Ebola Registry with ties to hospitals, ETUs, and communities to help family members track down lost loved ones (recommended partner – IFRC)
- Implementation of a uniform policy for managing all dead during the Ebola crisis either burial or cremation – so as to avoid "interpretive flex" in communities with dead people and no testing facilities

# Issue 2. Cremation

Many respondents supported cremation on public health grounds, recognising that it was a temporary emergency measure. Among those who supported cremation, there was considerable debate about how to manage the ashes. In order to make cremation culturally acceptable, several people recommended creating a mass grave site for cremated ashes, where loved ones could gather to remember the dead. Others wished to have the ashes returned to the family, as a token of remembrance or as proof that their loved ones had in fact died and been cremated. Still more were worried that even after cremation, the ashes posed sources of infection, and argued that the government should retain control over the ashes.

A minority of respondents was opposed to cremation on the grounds that it was inconsistent with traditional practices and beliefs, which were detailed in the study. Noting that,

"Cremation is not a good idea because it's not a part of culture," or "That we came from dust, and to dust we should return, so we should bury the bodies," respondents insisted that burial was a culturally important way of remembering and honouring the dead. There was also opposition to cremation because family members would have nowhere to go to remember the dead. There was considerable scepticism about whether or not it was "the government's" proper place to be managing funerary practices, as this was seen as a private familial and communal concern.

Many people in the community do not associate a mass burial site for ashes with the process and legislation mandating cremation for Ebola-infected corpses. Therefore, there were many comments like the following: "if cremation is allowed there is no burial site for family members to visit."

# Author recommendations:

- Cremation is not popular, but it is not universally disagreed with either. The government has done an effective job at persuading many people in communities that corpses are infectious.
- The global Ebola response has failed to provide communities with alternatives when corpses are not collected. It should:
  - Make a conclusive determination about cremation vs. mass graves vs. private burials. Determination should be based on available resources, not ideal conditions.
  - Provide detailed instructions to community members about how to handle corpses when they are not collected by health teams or burial teams.
  - Provide specific information about managing community-based cremations.
  - Create mass grave for cremated ashes where loved ones can go to remember families, where family members are remembered with their names inscripted on monuments.
  - Implement memorialisation practices immediately.
  - Return ashes to families if requested.
  - Assure population that cremation is a temporary measure.
  - Eliminate special exemptions for Ebola burials if cremation is the policy.
  - Religious spaces for each religion should be provided for at cremation sites.

# Issue 3: Mass burials

Support: Many felt that mass burial grounds were a superior solution to cremation, and some even recommended the creation of mass graves in every county in Liberia. Mass burials provided community members with a place to remember the dead. However, mass burial sites were also seen by some as being a good solution to the problems posed by cremation. Some suggested that mass grave for ashes should be established as a tribute, effectively serving the same function as a mass burial grave.

Opposition: A recurring fear in Monrovia communities centred on the seeming disappearance of both sick people and corpses who had been removed by health teams and burial teams. Specifically, citizens called repeatedly for the provision of some kind of evidence that their loved one had died and had been properly buried or cremated. One person suggested that the government ask specific families to provide burial sites for their loved ones, which many not have been technically feasible, but certainly echoes the sentiment that families would like direct involvement in determining the treatment of their family members' bodies.

There were concerns about how mass burials would impact ongoing debates regarding land ownership and land tenure. There was also widespread concern about environmental pollution.

### Author recommendations:

- Mass burials are preferred to cremation because they offer a place for people to go and remember family members.
- This is not straightforward. Mass burials are tied up with intense public concerns regarding environmental pollution and land reform issues.
- Religious spaces for each religion should be provided for at mass burial sites.
- Engage in public health messaging to provide correct information about whether or not the burial of infectious corpses and cremation results in soil, water, and air contamination.
- Issue a public statement concerning the issue of land ownership and mass graves. Consult with Land Reform Commission.
- Any sites selected for mass graves must not be currently contested property. Consult with Land Reform Commission.
- Mass burials can integrate traditional aspects of burial practices from ethnic groups across Liberia, but it must be recalled that Monrovia has a highly heterogeneous population, and no one religious, ethnic, or class-driven set of practices should dominate the process of mass burial, the organization of mass burial spaces, or the processes of memorialisation.

# Issue 4: Memorialisation

In the second WHO/GOL study, conducted during September 2014, community members made specific recommendations for memorialisation. They included:

- The declaration of an annual day of remembrance, day of memorial, or "Black Day"
- The construction of a memorial inscribing the names of every person who died during the Ebola epidemic
- The assignment of a mass grave/memorial site where people could go to remember their loved ones
- Funerary parades to honour the dead
- The creation of a scholarship program to support Ebola orphans through their educations
- The creation of funding programs to help communities support Ebola orphans feeding, clothing, and wellness through their childhoods

**Response to Ebola Virus Disease (EVD) in Lofa County, experiences from the field** Partners' Meeting Monrovia 11th October 2014. PowerPoint Presentation. http://www.timothypflaniganmd.com/wp-content/uploads/2014/10/lofa.pdf

# Factors that contributed to reduce new infections:

# Community engagement:

- Advocacy meetings with local leaders and other resistant communities
- Local leaders spearheading spread of messages in their communities e.g. Barkedu, Kornosue and Sheriff Quarters
- Prompt removal of alerts (use of hotlines & referral services)
- Community initiated restrictive measures including establishment of watch groups & compulsory washing of hands
- Involvement of youth and women groups as peer mobilizers
- Religious groups organize sensitization meetings with their faithful and preach on Ebola during every service/ worship
- Community cooperates to report and monitor all people who enter the county from other parts of the country

Community handling & burial of dead bodies:

- No community member is involved in physical handling and burial of community deaths
- Communities call the hotlines (if accessible) or inform the DHOs of any community deaths for safe burial
- With exception of Salayea (burial team to be trained), all districts have burial teams selected by the community, trained and facilitated
- Burial procedures explained to the community (encourage their participation & family wish respected) and affected house disinfected/sprayed

Referral of alerts from the community:

- General Community Health Volunteers (gCHVs) are assigned to follow contacts in collaboration with local chiefs and DHOs
- Very few contacts lost to follow up (0.6%)
- Contacts rarely run away from their location; they cooperate to be followed up for 21 days
- Patients whose first test is negative from the Case Management center are followed up in the community for 21 days
- People who come from other parts of Liberia into Lofa County are also followed for 21 days

Social Mobilisation and Communication:

- Advocacy meetings with County and District authorities, Community, religious and traditional leaders, women and youth groups, and communities considered resistant
- All affected communities reached with health messages- people are aware of Ebola
- Health education accompanied with distribution of hygiene kits and demonstration on hand washing
- Various communication outlets used: community radios, interpersonal communication, posters, focus group discussions and community outreaches
- Testimonies from Ebola survivors to increase confidence in the affected communities
- Collaboration between social mobilization and surveillance (alert & contact tracing) in communities that continue to report cases (hotspots)
- "Social mobilizers are mainly sons and daughters of the county who understand the local customs and traditions; making it easier to accept Ebola"

Lessons learned:

- Adequate community engagement is key in the overall response
- Denial, fear, panic, traditional practices and running away of contacts contributed to the exponential increase of cases and deaths
- Slow response in the initial phase of the epidemic resulted to increase in cases and deaths as well as fear and panic among the population and health workers. In this context, counties with weak capacities should be assisted robustly from onset of the outbreak
- Weak logistical capacity and bureaucratic procedures retard efforts to urgently interrupt transmission of the EVD
- Sustain community involvement and support to local authorities until the situation improves in the affected neighboring counties

# A Communication Response to Ebola in West Africa

Serlemitsos E. 2014. PowerPoint Presentation - Monrovia, Liberia, 17 December

(Not available online)

Social mobilisation response in Liberia:

- Training Training 10,000 gCHVs
- Messages and Materials Development and updating of Key Message Guide; and materials review process
- Media and Documentation Liaison with Ministry of Information
- Field Operations Oversight of field activities, including E-CAP
- Research, Monitoring and Evaluation National KAPs and Monitoring Framework

In Lofa county, now considered 'Ebola-Free', Community leaders engaged with the communities to get the key messages across:

- Ebola is real
- Do not touch sick people or people who have died (or their possessions)
- If your household was affected, you must stay away from other people for 21 days

Community leadership and community engagement is still key, but messages are evolving: (People all agree now that Ebola is real)

- Do not touch people who are sick or people who have died (or their possessions)
- Accept the ambulance teams, burial teams, case investigation teams, contract tracers into your communities- they are there to help
- Welcome back the survivors- they can no longer infect anyone (except for unprotected sex for up to 3 months)

# Is the Response in Liberia Succeeding? Positive indications

Bar-Yam Y. 2014. New England Complex Systems Institute (October 17). http://necsi.edu/research/social/pandemics/liberiadecrease.html

The number of cases of Ebola in West Africa has been growing exponentially, and projections assume that this dynamic will continue. However, recent case reports from Liberia indicate a change. The number of new confirmed cases reported by WHO has actually diminished for five weeks in a row. The WHO report suggests that this may be due to underreporting under conditions of high levels of stress of the number of cases taking place. Here we report that there appears to be a sound reason for the decreasing number of cases—a change in response strategy that is working. Understanding this dynamic is of critical importance for addressing the outbreak in Sierra Leone and Guinea. In particular the number of cases in Sierra Leone continues to grow exponentially. Discussions with a WHO response coordinator in Liberia indicates that a change in strategy from individual reporting and contact tracing to community based screening for early detection and population wide behaviour change happened in mid-September.

The WHO reporting of Ebola cases in Liberia is showing a rapid decline in the recent weeks from mid-September to mid-October. The reports do not suggest that this is a success story, rather warning about the limitations of data collection during a period of widespread disease. Still, it is important to note that if the prior rate of growth continued, the number of cases would have more than doubled till the middle of October. Instead, reported cases have decreased dramatically. The number of confirmed cases in particular has declined from a maximum of over 250 in the week ending Sept 7, to approximately 20 in the week ending Oct 12.

From personal communication with WHO Liberia-Monrovia response coordinator Dr Joa Ja'keno Okech-Ojony, we have learned that this trend may indeed be real. The difference in transmission is attributed to four changes that occurred in mid-September that can be responsible for this change:

Door to door screening once or twice per day of neighbourhoods for early identification of those with fever for isolation during the critical 72 hour period after symptoms begin to prevent contact and transmission.

Community teams that know each individual and are going door to door.

Public awareness and recognition of the danger and associated behavioural changes that are needed to prevent transmission. Global intervention partners, i.e. larger resources available from the international community for the response, including the construction of Emergency Treatment Units (ETUs). He notes that the primary difficulty continues to be the high density and contact rates in the urban environment of Monrovia which present significantly greater challenges for screening and isolation.

These methods confirm the effectiveness of key concepts of a recent proposal put forth by the New England Complex Systems Institute for response to Ebola in West Africa. Community based screening for early detection and population wide behavioural change are strategies that are fundamentally different from the traditional accepted response method in which individual reports of disease are followed by contact tracing. While specific adverse cultural behaviours, e.g. burial practices, are often mentioned, general public behavioural change is not discussed as integral to the response. We are pleased that the national response anticipated our proposal and appears to be succeeding.

The implications are that the current dynamic actually corresponds to a change in the transmission rate and thus an exponential decline in number of new cases. The authors note in contrast that the conditions in Sierra Leone continue to deteriorate. Understanding the mechanisms for success in Liberia may inform the efforts to contain the disease in Sierra Leone and Guinea, as well as strategies for future outbreaks.

# Community-Centered Responses to Ebola in Urban Liberia: The View from Below

Abramowitz S et al. (date unknown) http://www.academia.edu/9243932/Community-Centered\_Responses\_to\_Ebola\_in\_Urban\_Liberia\_The\_View\_from\_Below

The objective of this study was to identify epidemic control priorities among 15 communities in Monrovia and Montserrado County, Liberia – one of the hardest hit areas by the current Ebola outbreak. Findings from 15 focus group discussions with 386 community leaders identified specific strategies currently being undertaken and "ideal-typical" representations of what a community-based response to Ebola should look like. Data were collected on the following topics: prevention, surveillance, care-giving, community-based treatment and support, networking/hotlines/calling response teams and referrals, management of corpses, quarantine and isolation, orphans, memorialisation, and the need for community-based training and education.

Findings have been presented as recommendations for (1) Prevention, (2) Treatment and Response, and (3) Sequelae. The study also reviewed issues of fear and stigma towards Ebola victims and survivors, examined communities could draw upon survivors as resources in the outbreak, and studied how communities could provide psychosocial support to those who have been affected by Ebola. The findings provide several models that can inform international and governmental support for community-based management of the current Ebola outbreak.

Engaging local communities in Ebola response will require answering their challenging questions about their encounters with systemic failures. Communities are seeking guidance for how to proceed with a sick individual when they are turned away from hospitals, for building and supporting holding units in communities, and for reporting deaths when their

calls to hotlines go unanswered. The global health response needs to consider what it would mean to put into place surveillance and reporting mechanisms in which community-based leaders have the ability to directly account for health, illness, or death of every individual in the population, through the creation of a health identification number, through a creation of health census lists, or through some other mechanism of reporting and marking. In a context in which every death is an Ebola death because there are no community-based testing facilities for Ebola, every death needs to be counted as worthy of being reported. (And when everyone has a number, everyone counts.)

In the long term, equipping local communities with the material and knowledge resources to respond to Ebola within their own communities can help build a surveillance infrastructure that can inform a stronger post-epidemic state architecture, though certainly comes as a "add on" to supporting medical infrastructure and professional surveillance mechanisms, which must also be prioritised. In the short term, however, the shifting of surveillance responsibilities to highly structured hierarchies within local communities can also politicize micro-networks of communities in ways that may result in violence or remilitarisation of disenfranchised youth communities. That risk can be moderated, in part, by ensuring that required daily resources like food, medicine, housing, PPEs, and other resources are in abundance, and are not the subject of competition within and between groups during the epidemic.

# Medical Anthropology Study of the Ebola Virus Disease (EVD) Outbreak in Liberia/West Africa

Omidian P et al. 2014. WHO http://www.medbox.org/medical-anthropology-study-of-the-ebola-virus-disease-evd-outbreakin-liberiawest-africa/download.pdf

This study aimed to better understand the local beliefs and practices likely to enhance or hinder efforts to respond to the outbreak in Liberia. It argues that it is important to consider this outbreak as a larger humanitarian crisis rather than just being about a disease. The weak health system was completely closed for most of the time of this study, meaning no one was able to receive health care. Also, as numbers of infected have grown and borders/ports have closed, the economy of Liberia has weakened further. Each day that markets are closed poor women who work there lose the opportunity to provide for their families. This is a country of deep poverty and this outbreak is adding to their deprivation.

People are stressed and even re-traumatised because of memories of their lives during the war that ended only 11 years ago. The war experiences affect how people react to government messages. One person told me that there is no trust in the government and their messaging reminded him of the war when there would be a message over the radio of troops taking over an area when it was not true. When the president of Liberia declared a national emergency shops people queued in long lines to stock up on food staples like rice and oil. Most telling of the way people respond is in how people flee an area to go to another part of the country when they perceive danger. When someone dies of Ebola, it is common for survivors to pack up and move to another area. Those who are rural may go to family members living in an urban area, or they might move to another county where they cannot be easily traced. This practice, appropriate in wartime, has contributed to the spread of the disease. Also, everyone is told that if their loved one, including their own child, who exhibits such common symptoms as fever with headaches, diarrhoea and vomiting must not be touched. At least in a war, one can care for one's loved ones. It is no wonder that people are not able to believe what they hear from their government.

This is a humanitarian crisis that need to have a multi-sectorial response. The critical need for health services is obvious to all, but, like in a warzone when people are traumatised or displaced, other services need to be included. It is important that basic needs of food, shelter and livelihood are protected or provided. Also important, but more difficult to address are the

emotional needs and social needs within communities. This is particularly important for the mental well-being of people in high context cultures like those in Liberia. A disease that can only be stopped when people stop touching each other and caring for their sick loved ones has a horrendous impact on the emotional wellbeing of those very family members. Schools and colleges are closed, disrupting routines for children, increasing stressors for them and their care-givers and impacting the social needs of children.

The following recommendations are given:

- There is a need for a 2-tiered strategy with the continuing effort to open health facilities and treatment centres
- Community leaders and civil society must be mobilized from household level upward
- Give people something to do
- Response is needed to address this humanitarian crisis through a multi-sectorial approach

The following community issues are important to consider:

- Involve religious and community leaders in all aspects of the Ebola response, from education on prevention, transfer to treatment centres, to contact tracing and burials.
- Increase involvement by civil society.
- There should be at least one trained person in every community to educate people on key Ebola signs and what to do if someone is sick. This could be a village health worker who is already trusted:
  - This person can educate community members on what to do for a person who exhibits symptoms, while they are waiting for services or want to transport someone to a treatment unit.
  - If there is a person suspected to be an Ebola patient and they have children, the community leader or someone designated by the community should take care of the children so that they do not get infected.
  - Each community should receive items for washing hands (buckets, chlorine, etc).
  - It is important to involve families in the care of their loved ones as much as possible so that they can give moral and emotional support. This would also reduce the distrust families have of the ETUs.
  - Give information to families on all aspects of the process so that they can understand what is happening. This is also important regarding burial procedures.

The following communication issues are important to consider:

- There is clearly miscommunication around the issue of burial and whether or not the community fills in the grave after the burial team has put the body there. This much be sorted and information shared.
  - Keep the messages simple and few in number and train local spokespersons to answer questions that may arise.
- Representatives from each county (at least 5) should be trained to on the ebola awareness message and to work with a designated person in each village in their area.
  - People should be educated on how the virus is transmitted. It is important to address their fears. Information on what to do and why you should do it is needed. If people are not told why, they are less likely to follow instructions.

In terms of the Ebola Response, there should be the following:

- At least one health and burial team in each district.
- More than one ambulance per county.
- Information for family members about the burial process of their dead relatives. If possible, a family member could accompany the burial team to the cemetery.

- In cases of cremation, the ashes can be returned to the family so that memorial activities can be conducted.
- It is important to describe disease transmission in terms that people can understand—such as local examples like "the chicken sickness". Also the concept of a disease reservoir can be explained so that people understand why they are told to avoid fresh bush meat.
- It is important to open health care facilities across the country to deal with other illnesses, diseases and accidental injuries.
- Open more Ebola Treatment Units and Holding Centres across the country, particularly in counties with the greatest number of cases.
- Children have special needs, which could be managed best with special Ebola treatment centres designated for them. These centres could be affiliated with existing centres but would be child-friendly spaces.
- Every health care worker must know that every patient is a potential Ebola patient.
- Health workers should have training and use of PPEs, with a strengthening on universal precautions.
- It is possible to re-enact ceremonies that were used during the war years when family members died but there might not have been a body to mourn. During that time there were a variety of rituals to commemorate the dead: warrior dances, planting of trees, or night-long candlelight vigils in front of a picture of the deceased. Communities could be encouraged to bring some of these back.
- The government could consider creating a memorial park or gathering place so that families would have somewhere to go to remember their dead.
- People have the basic messages. It is time for the next level of information
- The messages also need to shift so that people have something they can DO. Without something to do, people react. People need to be able to take positive action An Example of "Something to do..." is as follows:
  - If someone in your house is sick and you cannot get them to a center (or while you wait for help to arrive) have only one family member be the designated care provider. Isolate person from all other family members, and especially the children. Remember the rules—i.e., no contact with body or body fluids. Stock the following items (chlorine, ORS, etc.)

# Liberia: handling of bodies and national memorials – community perceptions from Monrovia

# Bedford J. 2014 b. UNMEER

ttp://www.ebola-anthropology.net/wp-content/uploads/2014/11/Liberia-handling-bodies-andnational-memorials.pdf

This brief summarises attitudes of community leaders and residents in and around Monrovia. It is intended to provide an evidence base to support the SOP on safe and dignified burials, and to contribute to ongoing discussions about mass graves and national memorials. It recommends the following:

Evidence of death and the proper handling of bodies:

- Introduce identification card for all admitted patients that will be returned to families after the patient's death.
- Introduce patient information board outside each facility that is updated daily, this would serve as a registry that community leaders could add to and report on.
- Ensure families are informed when their relative dies.
- Share in detail with community leaders the procedures being implemented for the correct handling of bodies.
- Take a photograph of each deceased patient (with their identification card) and present it to their family.

Mass gravesite:

• Mass gravesites should be for both bodies and ashes.

# National monument:

• To introduce an annual National Memorial Day for Ebola

# Annual Grave Cleaning Day:

• Start to make appropriate preparations for Grave Cleaning Day (12 March 2015).

False burial and death ceremonies:

• There is a practice of false burial in some areas of Liberia (in which the body is often kept above ground for quite a while). This needs further investigation but is of potential significance.

# 4. Experience from Sierra Leone

# Study on Public Knowledge, Attitudes, and Practices Relating to Ebola Virus Disease (EVD) Prevention and Medical Care in Sierra Leone

UNICEF, FOCUS 1000, and Catholic Relief Services. 2014. UNICEF, FOCUS 1000, and Catholic Relief Services.

http://newswire.crs.org/wp-content/uploads/2014/10/Ebola-Virus-Disease-National-KAP-Study-Final-Report\_-final.pdf

Key recommendations for social mobilisation and behaviour change communication:

- Address misconceptions about the disease;
- Avoid fear-based messages as they may discourage prompt medical seeking behaviours
- Clearly spell out modes of transmission in the local languages;
- Develop clear messages in local languages on protective practices (including burials);
- Develop special messages around community acceptance of Ebola affected persons and
- families;
- Maximally use radio as it is the most preferred channel with the widest geographic reach;
- Support inter-personal engagement at grassroots level in order to improve community response and ownership of the social mobilization efforts;
- Effectively use television medium to tell survivor stories and create a hopeful narrative;
- Strategically engage religious leaders via churches and mosques in disseminating key
- Prevention messages using a faith-based lens and perspective;
- Ensure that key information is communicated directly by health professionals and GoSL/MoHS because they are the most trusted source on Ebola.

# Radio by far the preferred means for receiving information about Ebola

Not only does radio have the widest reach, it is also the most preferred channel with 85% of respondents preferring to get Ebola related information through the radio. This is followed by house visits by health professions, television, and religious venues (mosques/churches). In the epicenters, house visit by health professionals is the second most preferred means of receiving EVD information (54-63%). Television is more preferred in urban settings such as Western Area and Bo Town as compared to rural parts of the country.

Health professionals and Government/MOHS: the most trusted source of information Health and medical professionals are perceived to be the most trusted source of information on Ebola related issues (60%). In the Kailahun and Kenema, the level of trust of health professionals ranges from 70 to 86%. Health professionals are least trusted in Western Urban (43%). The second most trusted source of information is the Government/MoHS (48%).

# **Trigger Behavioral Change to strengthen community's resilience to Ebola Outbreaks** ACF International. 2014.

http://reliefweb.int/sites/reliefweb.int/files/resources/Trigger%20Behavioral%20Change%20to %20strengthen%20community.pdf

In order to respond to the context and the needs, ACF in Sierra Leone has designed and piloted the "Community Led Ebola Management and Eradication" (CLEME) approach in Moyamba District. This approach responds to the deeper need of SM to trigger behavioral change in order to strengthen community resilience to EVD outbreak. All levels of the society need to be empowered to lead the Ebola response, particularly the communities.

The CLEME approach provides the communities with the tools to identify their unsafe practices that could lead to potential EVD infections and to identify solutions that fit the individual and community's needs, culture and available resources.

In the communities where ACF has piloted this innovative approach, the organization has broken through the reluctance of the communities to adopt specific behaviours to prevent the virus transmission and has successfully engaged community volunteers in surveillance activities ensuring that safety measures are implemented at community level and that risky behaviours are not adopted.

The initial results of the CLEME approach are encouraging. Following the triggering most of the communities immediately decided to take actions to address the identified risks designing their own Ebola community action plan.

A community action plan was developed also in the quarantined communities and was shared by the team with each household. However, in consideration of the movement constraints, the implementation of the plan was postponed at the end of the 21 day quarantine period, when movement is possible.

Project progress and lessons learnt:

- Overall all the targeted communities have demonstrated awareness of the EVD and all of them have identified a community action plan;
- 10 communities have hand washing facilities at household entrances
- 10 of the triggered communities have established a "community support group" that is willing to support the DHMT at community level conducting active surveillance, referral and SM. The 2 remaining communities are the quarantined ones that couldn't meet at the time of the pilot to decide on the establishment of CSG;
- In the 10 communities where the CSGs were established, ACF were requested to support and coach the identified volunteers on their specific roles. This coaching activity was conducted and the CSGs are now functional;
- 8 communities have identified a 24hrs (maximum) isolation unit in their communities where they can isolate sick people. Of these, 5 communities have identified abandoned households, and 3 external rooms. These places have been identified by the community, and are based on their capacity to isolate suspected patients to avoid infection.
- 10 communities have established by-laws for Ebola prevention, covering activities such as reporting sick people or having traditional burials.

#### Is sensitisation effective in changing behaviour to prevent Ebola transmission? Start Fund. 2014. Project Case Study. http://www.start-network.org/wp-content/uploads/2014/09/Start-Fund-SLE-case-study.pdf

ActionAid, Christian Aid, Concern and Save the Children responded to the ebola outbreak in Sierra Leone from 28 June – 12 August 2014 with Start Fund grants, a month after the first Ebola case was reported. This case study focuses on lessons learnt about community sensitization in the process.

This is the first Ebola outbreak in Sierra Leone so most people have no knowledge about the disease. Instead, there is widespread fear, anxiety and panic. This confusion in some cases has resulted in rumours and deep mistrust of the health workers and the response efforts. In the eyes of many people, loved ones who go to health centres with normally treatable symptoms never come back. The agencies urgently need to communicate with the population about the nature of the disease and how to control it.

Agencies had to rapidly sensitise communities to the facts about the disease. They teamed up with the Ministry of Health and Sanitation, community leaders, civil society organisations, other international agencies and local NGOs and health workers to organize widespread awareness campaigns. They had to be creative and cost-effective in maximizing their reach while giving each community enough attention to ensure a strong reception of the control measures. One of the agencies observed that the more time their teams spent in one location, the more interested the residents became in the messaging and more confident to ask questions and clarifications.

The production of radio jingles, posters, factsheets, banners, newspaper ads, and motorcade air jingles provided an indirect form of communication to the public. This type of sensitisation was useful for achieving a wide reach to reinforce key control messages but it did not allow for a two-way dialogue about the epidemic.

Direct sensitisation, on the other hand, such as performing door-to-door campaigns and organising community meetings to discuss the disease went further in appeasing fears and providing clarity about the causes of the epidemic and how to control it. This requires more capacity but it can increase the public's ability to recognize Ebola and adhere to prevention practices.

Analysis of the impact indicate that there was a clear increase in the awareness of Ebola and how it is transmitted and prevented. There was an increase from 39% to 85% of households correctly able to identify Ebola prevention methods. However, ActionAid also found that there was no significant improvement in the time it takes for potential cases to seek care. The responses roughly stayed the same with 33% claiming they would treat the symptoms at home for 3-4 weeks and 54% saying they would immediately go to a doctor. People's awareness is increasing but sustained efforts are needed to change actual behaviour.

Whether the sensitisation activities are effective in shifting behaviour and reporting suspected cases is of critical importance. Resources are stretched and time is of the essence. Anecdotally, the Start Fund projects did observe some specific short-term changes, such as lower attendance at funerals, increase in hand washing and using gloves, decrease in hand shaking and increase in precautions from frontline health workers when caring for patients. These are encouraging signs but attention should continue to be focused on identifying the specific sensitisation actions which led to these outcomes and behavioural changes.

# SMAC Situational Report: 01/12/14-07/12/14

# (Not available online)

Social Mobilisation Action Consortium (SMAC) is a group of five agencies working within the MoH Sierra Leone National Social Mobilisation Pillar to achieve the National Social Mobilisation Strategy and contribute to achieving zero new cases of Ebola Virus Disease (EVD) in Sierra Leone. SMAC has national coverage and is currently funded by the Department for International Development (DFID) to implement the Community-based Action Against Ebola project (15/10/14 - 15/04/15).

Activities include: national social mobility support, training radio producers, training religious leaders, and triggering/supporting community mobilisers.

Snapshot of success:

- Community Mobilisers in Western Area are being called by their communities when incidents occur; this week a patient was refusing to get in the ambulance and the community called the Mobilisers to come and talk to the family
- The death of a popular local teacher at Njala attracted the attention of about 200 residents who wanted to witness the burial ceremony during the Ebola crisis because they felt safe attending after listening to one of our partner station's broadcast (Njala University Radio) on SOP that week. Following the safe, dignified, medical burial ceremony, residents were pleased with the process and expressed willingness to comply with the new burial procedure thereby creating trust between the community and the burial team
- Members of the NERC Media Group were impressed with SMAC's approach in training and supporting partner stations to produce local programmes that meet the needs of local audiences and how it's bringing out stories of change and impact from the community through coordination with other consortium members. There may be an opportunity to leverage the SMAC network of media, social mobilisers and religious leaders to better engage and communicate with people living in districts in the Ebola emergency response.

# Challenges/Setbacks:

- Difficulty getting some community stake holders for the triggering sessions as some members will only be available after working hours.
- Community Mobilisers do not have smart phones yet as due to change in community mobilisation approach (CLEA) it was deemed inappropriate to give out phones during same training for fear the phones would detract from the learning and focus on CLEA and deep IPC. However, bringing all the Mobilisers back for second training is a big undertaking which needs careful planning.
- Splash payments are still presenting difficulties and delays. Issues are being tackled by central offices.
- Regional admin and finance (Restless Development) requires significant support from head office.
- WAS is taking up a lot of time and needs strong support on the soc mob side, positive focus but SMAC personnel also need to continue to provide strong support to newly-dispatched Mobilisers who are already achieving a lot. Also concern that if services aren't ready and/or if Mobilisers are dispatched to give messages via megaphone or otherwise aggressive means it could cause trust issues at community level.
- High turnover of international staff is making coordination very difficult.

#### Homegrown Good Practice Responses to Ebola in Sierra Leone. Research Summary. King N. 2014. Grey literature. (Not available online)

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Culturally-rooted practices and longstanding governance challenges have facilitated the spread of Ebola in Sierra Leone. Yet variations in these across districts offer potential lessons for combating Ebola. This Summary highlights initial ideas from research conducted with respondents in Kailahun, Kenema and Koinadugu:

- Compensatory burial practices might address obligations for contact with the dead
  - Respondents have indicated that resorting to later collective ritual may prove an acceptable "compensatory mechanism" in satisfying obligations. Committing to support collective memorial rituals of sufficient scale as soon as conditions allow, could provide the needed assurance and incentive to refrain from immediate, direct-contact burial practices.
- Emphasizing the material benefits of testing and quarantine centers can enhance uptake
  - Citizen cooperation may be increased by messaging that highlights the material benefits of testing and quarantine centers (food, medicine, other supplies); resources, of course, must be available to ensure expectations are met.
- By-laws are being employed as instruments of behavioral change.
  - The risk of immediate and locally enforced monetary penalties can be effective even when the threat of severe health consequences for the same behaviour is not.
- Sexual intercourse by survivors may be contributing to transmission
  - Treatment centers, re-integration counseling (where in place) and outreach efforts should devote greater emphasis in sensitizing males and females to this transmission modality, while taking care to avoid further alienating or stigmatising survivors.

# Big changes found in rural communities in ebola awareness and response

Richards P & Mokuwa E. 2014. Njala University. Grey literature. Not available online.

The present report is restricted to data collected for villages associated with the Sierra Leone Fogbo outbreak: 1) Fogbo, 2) Foindu and 3) Moyamba Junction.

Sampled informants in all three places had accurate and realistic knowledge about Ebola and the Ebola infection chain. Informants differentiated accurately between things they had been told (by health workers, and over the radio) - for instance, that Ebola was spread by bushmeat - and things that they knew from their own experience (they gave accurate accounts of the symptoms of Ebola, and could clearly explain the way it had spread, e.g. by touching corpses). Some of the information was specific to a notable case - a respected retired pharmacist at Moyamba Junction who was an early victim, and whose sickness and burial spread the disease to many sympathisers. Informants made it clear they understood that his funeral had led to numerous further infections. It was widely reported that as a result of this experiential change people now protected themselves by strategies of avoidance. They did not visit the houses where cases were known (marked by red tape), and avoided direct body contact. They were also now very careful about personal hygiene (e.g. washing hands frequently). It was also reported by some informants that families with cases applied a one-on-one care model (only one relative should directly care for the patient). Further work on the data set (or thorough follow up) is needed to know if this change in normal practices of care for the sick was based on information provided by health workers or worked out by people themselves. That body fluids from Ebola cases were dangerous was widely understood and reported.

The surveys and focus groups provided much new and valuable information on burial practices. This was a practical outcome of the research design (choosing a cross border sample of villages) since people were anxious in their focus group sessions to clarify the correct procedures for burying Mende and Temne people. They also frequently emphasised the burial requirements of Islam, and explained (with some vehemence) how the actual
practices of Ebola burial teams flouted cultural and religious requirements. The situation was a cause of great dissatisfaction. One instance given was the way burial teams moved bodies around by levering them with sticks or poles, instead of correctly and respectfully lifting them by human hand. The use of sticks to ensure the body had reached the base of the grave was also commented on unfavourably. Ethnically-specific practices were mentioned that seemingly have relevance for assessment of infection risk. It was claimed that, in Temne communities, washing of corpses was always done by women, but in Mende communities women wash female bodies and men wash male bodies. Again, some further checking needs to be done, but if this is correctly reported, then (to the extent that body washing is a means by which significant numbers become infected) this would show up as a gender imbalance of cases in Temne communities (more women should be infected). A nul result on this criterion might indicate that corpse washing is a less significant infection pathway than hitherto claimed (data to be provided). Informants also spoke about important ritual practices. In some cases, dirt is taken from the grave site and applied to Temne widows. A perhaps more significant infection risk inheres in the subsequent ritual use of grave cloths. Among the Mende, informants reported that where a child has died, the last child is given the grave cloth and told to wash it. It then becomes a memento of the lost sibling.

# Local beliefs and behaviour change for preventing Ebola in Sierra Leone

Grant C et al. 2014. HEART Helpdesk http://www.heart-resources.org/2014/11/ebola-local-beliefs-behaviour-change/

This report focuses on the local beliefs and practices around illnesses and death, the transmission of disease and spirituality, which affect decision-making around health-seeking behaviour, caring for relatives and the nature of burials. It also considers how this can inform effective behaviour change interventions for preventing Ebola in Sierra Leone. Four key transmission pathways are considered; unsafe burial, not presenting early, care at home and visiting traditional healers.

Indigenous beliefs and responses to Ebola are rarely mentioned and when they are images of ignorance, exoticism and superstition are what prevail. However, social mobilisation is a key component because all stakeholders should be involved to enable pooling resources and optimising management of epidemics, this is especially important with Ebola due to the poor specificity of symptoms.

There are many areas where behaviour change can have a positive effect but ethical aspects should not be overlooked and this is now being recognised in scientific papers as well as in anthropological circles. Isolation of patients, required to avoid contamination, should not be seen as segregation. The family should be able to see and talk to patients, even if they are prevented from touching them. Authorities and medical staff should comply with, as far as possible, funeral rites by providing body bags and coffins for the families. For instance, decontamination will be presented as ablutions that can be associated with the current ritual; deceased's clothes will be buried in the grave rather than burned to prevent stigmatisation and other such culturally sensitive actions.

People interpret and respond to disease in line with longstanding local frameworks. Public behaviours and attitudes that might at first sight appear to reflect ignorance, can and should be seen as part of cultural logics that make sense given regional history, social institutions and experience. Viewing conflicts as stemming from opposing categories of traditional and modern does not capture the complex and emergent meanings which define life in this region and this epidemic.

This paper explores local beliefs and practice, how these influence health seeking behaviour and what behaviour change interventions are appropriate, it was prepared as a rapid response briefing, so covers these issues in brief detail.

# Social pathways for Ebola Virus Disease in rural Sierra Leone, and some implications for containment

Richards P et al. 2014. PLOS Neglected Tropical Diseases http://blogs.plos.org/speakingofmedicine/files/2014/10/Richards-et-al.1.pdf

The current outbreak of Ebola Virus Disease in Upper West Africa is the largest ever recorded. Molecular evidence suggests spread has been almost exclusively through humanto-human contact. Social factors are thus clearly important to understand the epidemic and ways in which it might be stopped, but these factors have so far been little analysed. The present paper focuses on Sierra Leone, and provides data on the least understood part of the epidemic - the largely undocumented spread of Ebola in rural areas. Various forms of social networking in rural communities and their relevance for understanding pathways of transmission are described. Particular attention is paid to the relationship between marriage, funerals and land tenure. Funerals are known to high-risk factor for infection. It is suggested that more than a shift in awareness of risks will be needed to change local patterns of behaviour, especially in regard to funerals, since these are central to the consolidation of community ties. A concluding discussion relates the information presented to plans for halting the disease. Local consultation and access are seen as major challenges to be addressed.

# Sierra Leone: Gift giving during initial community consultations

Bedford J. 2014. UNMEER http://www.ebola-anthropology.net/wp-content/uploads/2014/11/Sierra-Leone-gift-giving.pdf

This brief summarises appropriate gift giving during initial community consultations in Sierra Leone. It is intended to provide an overview of good practices to support UNICEF, the WHO and other agencies as they interact with Paramount Chiefs prior the implementation of CCCs. It does not focus on the community consultation process more broadly, but specifically on gift giving during the first meeting.

# 5. Experience from Uganda

### Cultural Contexts of Ebola in Northern Uganda

Hewlett BS & Amola RP. 2003. Emerging Infectious Diseases, 9(10). http://wwwnc.cdc.gov/eid/article/9/10/02-0493\_article

Technical guidelines for the control of Ebola haemorrhagic fever (EHF) indicate that understanding local views and responses to an outbreak is essential. However, few studies with such information exist. Thus, the authors used qualitative and quantitative methods to determine how local residents of Gulu, Uganda, viewed and responded to the 2000–2001 outbreak of EHF. Results indicated that Acholi people used at least three explanatory models to explain and respond to the outbreak; indigenous epidemic control measures were often implemented and consistent with those being promoted by healthcare workers; and some cultural practices amplified the outbreak (e.g., burial practices). However, most persons were willing to modify and work with national and international healthcare workers.

Seven things we can learn from the Ebola Epidemic in Uganda in 2000 – 2001 Ssali S. 2014. HEART Blog. http://www.heart-resources.org/blog/seven-things-can-learn-ebola-epidemic-uganda-2000-2001/ A list of the interventions undertaken by Uganda's Ministry of Health to combat Ebola included the following:

### Partnerships with communities

Upon realising that they could not do everything by themselves, the Ministry of Health decided to build partnerships with other actors within the community, such as non-governmental organisations like the Red Cross and World Vision. These partnerships were crucial for mobilising communities, information dissemination, and early case detection. Anti-government rebels stopped fighting and supported the anti-Ebola efforts.

#### Community-based disease surveillance

The Ministry of Health trained community members to provide a network for surveillance and public information. These community members rapidly reported suspected cases from households, who were rapidly assessed using history of contact and clinical assessment. This strategy was important in that it was not very costly to manage.

#### Work with the Media

Realising the role of the media in informing and misinforming the masses, given their previous role in propagating myths and rumours about Ebola, the Ministry of Health learnt very quickly that they needed to partner with the media to provide prompt and factual public information. Information dissemination could no longer be the preserve of health workers. The media was trained in Ebola and barrier nursing to protect themselves, after which they were charged with providing factual updates about the disease on a daily basis. This way, the media helped curb rumours, myths and risks associated with the disease.

#### Technology for quick field diagnosis of new infections

Because there was no special laboratory for testing Ebola in the country, a field laboratory for spot screening was provided with help from the Centre for Disease Control (CDC) and the World Health Organization. The South African Institute of Virus Research helped customise certain procedures to make them simpler and less costly. This helped with early detection, while those suspected but found to be negative were able to return to their normal lives. This helped reduce stigma and re-build trust between the communities and the health facilities managing Ebola.

#### Infection control and hospital waste management

While health facilities should routinely manage waste professionally, this is not the case, especially in rural communities. Moreover, no one had been prepared for the kind of waste management that accompanied an Ebola epidemic. Sometimes, health workers thought that ensuring that isolating people with Ebola was all they needed to do. In addition, there was need to protect non-health workers in the Ebola response, such as drivers. The Ministry of Health developed a programme to promote infection control in hospital and health facility settings. However, this training was not restricted to health workers, but to others such as drivers who transported cases to referral centres.

#### Work on the legal, ethical and social issues

One of the biggest challenges in combating infectious diseases arises from people's traditions and cultural norms. Such traditions, with respect to the Ebola epidemic, relate to burials in ancestral grounds, funeral ceremonies, and the handling of the dead. People were provided with information about the dangers of touching those who had died of Ebola and encouraged to leave burials to the specially trained burial committees. In addition, there were issues of disclosure and confidentiality, which posed ethical challenges to medical workers, and the several children (about 500) orphaned by Ebola. To address these, the government enacted the Workman Compensation. Individual confidentiality was suspended for public information sharing and counselling services provided to the orphans. In addition, a Post-Ebola Association and a special clinic opened to provide services to survivors.

## National and international collaborations

One thing that has been associated with Uganda's success in combating epidemics such as HIV and Ebola is the leadership and commitment from government. With the suspicion of Ebola in Uganda, despite meagre finances, the government embarked on a process of providing essential resources to help combat the epidemic. These essentials included but were not limited to; supplies, funding, expertise, communication, and information. Where resources became a challenge, the government called on the international community to help. Some of these, such as CDC, provided the expertise in field testing. All external actors were coordinated by the National Task Force. In addition, other tasks forces were established at the district (DTF) and between ministries (IMTF). These task forces included policy makers, such as district leaders, Members of Parliament, religious leaders, and the police along with people from the health sector.

#### **Regaining trust: an essential prerequisite for controlling the Ebola outbreak** Omaswa F. 2014. The Lancet Global Health Blog.

http://globalhealth.thelancet.com/2014/08/11/regaining-trust-essential-prerequisitecontrolling-ebola-outbreak

A trust gap has developed between the health system and the general population which has made control efforts difficult in west Africa. Lessons from the 2000 Ugandan epidemic include that building and holding public trust by the government and health personnel is the foundation for all control efforts. Ebola evokes fear and apprehension at individual and community levels, which easily results in herd responses, negative or positive. Intensive communication with the public can achieve this. Epidemic status reports were issued through press statements every morning, lunchtime, and evening along with a press conference each morning. The media are critical in building and sustaining trust and their own confidence has to be won.

Hotlines for anyone to seek or convey information were open 24 hours at the Ministry of Health Headquarters and at the District Medical Office in the affected districts.

Community or village leaders worked alongside the Village Health Teams. Controlling the epidemic is about early detection, isolation, treatment of new infections, contact tracing, and safe handling of body fluids and the remains of those who die. In Uganda this was achieved by building community trust of the public health system, including recruiting support and oversight by local formal and informal community leaders. Top Ministry officials moved to live in the affected districts to support and direct control efforts and the Minister and Director General visited weekly using helicopters to go to the villages addressing public meetings and inspiring local health workers.

Technology was introduced for quick field diagnosis of new infections. This enabled suspected but negative individuals to leave isolation quickly and return to normal life. It also enabled early initiation of treatment measures for those who test positive. This was the contribution of partners such as the US Centers for Disease Control and Prevention, who brought in the field laboratory, and WHO, that came with supplies and technical expertise to support and stay with us in Uganda. This global solidarity, however, can only work where there is effective local leadership that is trusted by the local population.

Finally, controlling an Ebola outbreak is about the strong primary health-care principles, including leadership from the top, integrated with routine governance of society and involving the active participation of the people themselves.

# An outbreak of Ebola in Uganda

Okware S et al. 2002. Tropical Medicine and International Health. 7 (12) http://onlinelibrary.wiley.com/doi/10.1046/j.1365-3156.2002.00944.x/full

Response measures for an Ebola outbreak in Uganda in 2000 included surveillance, community mobilisation, case and logistics management. Three coordination committees were formed: National Task Force (NTF), a District Task Force (DTF) and an Interministerial Task Force (IMTF). The NTF and DTF were responsible for coordination and follow-up of implementation of activities at the national and district levels, respectively, while the IMTF provided political direction and handled sensitive issues related to stigma, trade, tourism and international relations. The international response was coordinated by the World Health Organization (WHO) under the umbrella organisation of the Global Outbreak and Alert Response Network.

Guidelines for identification and management of cases were developed and disseminated to all persons responsible for surveillance, case management, contact tracing and Information Education Communication (IEC).

The Government's role in coordination of both local and international support was vital. The NTF and the corresponding district committees harmonised implementation of a mutually agreed programme. Community mobilization using community-based resource persons and political organs, such as Members of Parliament was effective in getting information to the public. This was critical in controlling the epidemic.

Past experience in epidemic management has shown that in the absence of regular provision of information to the public, there are bound to be deleterious rumours. Consequently rumour was managed by frank and open discussion of the epidemic, providing daily updates, fact sheets and press releases. Information was regularly disseminated to communities through mass media and press conferences. Thus all levels of the community spontaneously demonstrated solidarity and response to public health interventions. Even in areas of relative insecurity, rebel abductions diminished considerably.

# "A time of fear": local, national, and international responses to a large Ebola outbreak in Uganda

Kinsman J. 2012. Globalization and Health, 8 (15) http://www.globalizationandhealth.com/content/pdf/1744-8603-8-15.pdf

This paper documents and analyses some of the responses to the Ebola outbreak in Uganda in 2000/2001. This article includes responses to the outbreak in local, national, and international contexts over the course of the outbreak. Responses were gauged through the articles, editorials, cartoons, and letters that were published in the country's two main newspapers: the New Vision and the Monitor. All the relevant pieces from these two sources over the course of the epidemic were cut out, entered onto a computer, and the originals filed. A total of 639 cuttings were included. Strong and varied responses to the outbreak were identified from across the globe. These included, among others: confusion, anger, and serious stigma in affected communities; medical staff working themselves to exhaustion, with some quitting their posts; patients fleeing from hospitals; calls on spiritual forces for protection against infection; a well-coordinated national control strategy; and the imposition of some international travel restrictions. Responses varied both quantitatively and qualitatively according to the level (i.e. local, national, or international) at which they were manifested. The Ugandan experience of 2000/2001 demonstrates that responses to an Ebola outbreak can be very dramatic, but perhaps disproportionate to the actual danger presented. An important objective for any future outbreak control strategy must be to prevent excessive fear, which, it is expected, would reduce stigma and other negative outcomes. To this end, the value of openness in the provision of public information, and critically, of being seen to be open, cannot be overstated.

#### 6. Experience from Nigeria

#### Ebola Virus Disease Outbreak — Nigeria

Shuaib F et al. 2014. Morbidity and Mortality Weekly Report; 63. http://www.cdc.gov/mmwr/pdf/wk/mm6339.pdf

The ongoing Ebola virus disease (Ebola) outbreak in West Africa has had an enormous negative impact on civil and public health systems in Liberia, Sierra Leone, and Guinea. Nigeria's public health system includes a national public health institute (NCDC) and an Emergency Operations Center (EOC) and Incident Management System (IMS), created in 2012 when Nigeria declared polio a public health emergency and restructured its national polio program.

Applying lessons from its NCDC and successful polio EOC, Nigeria quickly established a National Ebola EOC after importation of the disease on July 20, 2014. The early use of the EOC/IMS system enabled the country to streamline a coordinated and effective response in Lagos, (pop. 21 million) and to expand that response to Port Harcourt, another large city. As of September 24, a total of 894 contacts in three states had been monitored, and 20 confirmed or probable Ebola cases identified, of whom eight died. No new cases had occurred since August 31, suggesting that the Ebola outbreak in Nigeria might have been contained.

African nations need to rapidly assess their readiness to manage the importation of Ebola. Preparedness activities could include planning EOC/IMS structures that can guide a coordinated and effective response to Ebola or any other public health threat. Where EOC already exists for other diseases like polio, such structures should be strengthened and used to mount effective responses to new threats like Ebola.

## In Nigeria, texting to prevent Ebola

Njoku G. 2014. UNICEF website. http://www.unicef.org/infobycountry/nigeria 76251.html?utm source=unicef news&utm medi um=rss&utm\_campaign=rss\_link

A text messaging communications platform developed by UNICEF has become a vital source of information in preventing the spread of Ebola in Nigeria.

Educating the public about Ebola transmission and prevention has been a critical part of the effort to contain the outbreak in Nigeria. In addition to house-to-house campaigns and other social mobilisation activities providing lifesaving information on Ebola virus disease, UNICEF has used the U-Report platform to reach a large segment of the Nigerian population.

"Within first 24 hours of the outbreak, our subscribers doubled from 19,000 because of the accuracy of information. Unsolicited responses were replied in real time. Questions, answers and facts from World Health Organization were shared on Twitter and Facebook on the measures to prevent Ebola," says Aboubacar Kampo, UNICEF Nigeria's Chief of Health, who oversees U-Report Nigeria.

"People were asking questions like: Does bitter kola cure Ebola? Is Ebola Virus Disease airborne? Does bush meat transmit Ebola? Can it be transmitted via mosquito bites?" Mr. Kampo explains. "These were the questions people were asking, because they want to know, and you cannot blame them."

In addition to the thousands of U-reporters sharing messages with friends and relatives, major radio and television networks in Nigeria rebroadcast U-Report messages to millions of their audience.

"We must never underestimate the power of the social media. With more than 100 million Nigerians owning a mobile phone today, they can get the right information or ask their question and get real-time response from others as quickly as possible," says Jean Gough, UNICEF Representation in Nigeria. "This is how to engage the communities and promote necessary social change that people want."

# In Nigeria, social mobilizers fight Ebola – and misinformation

Moser P. 2014. UNICEF website. http://www.unicef.org/infobycountry/nigeria\_75929.html?utm\_source=unicef\_news&utm\_medi um=rss&utm\_campaign=rss\_link

Educating the public about Ebola transmission and prevention is a critical part of efforts to contain the outbreak. In Nigeria, the information campaign is taking on an added importance as schools reopen. UNICEF is supporting a major social mobilisation effort through deployment of outreach teams door-to-door and to public gathering places.

7. Behaviour change and social mobilisation recommendations – not region specific

# Understanding Ebola

Wilkinson A. 2014. PowerPoint presentation. (Not available online)

Behaviour change depends on material realities:

- Quarantine, food insecurity, dying alone, no treatment, stories of no food and undignified care, and hospitals as vectors
- Catastrophic costs of Ebola can make it impossible to admit?
- Little practical help. Blame and punishment rather than support: "comb" neighbourhood for "Ebola suspects"
- People won't stop caring for loved ones

How can social and experiential learning lead to adaptive responses?

- Novel diseases challenge communities; can expect a 'learning curve'
- With experience, collaboration, access to practical information about spread, etiological understandings can shift regardless of scientific knowledge, leading to development of effective control protocols
- Process may occur with or without assistance and information from experts

Local control of Ebola outbreaks in communities in DRC and Uganda:

- Well documented evidence of 'indigenous protocols' to control spread of Ebola in communities since 1970s
- Often included:
  - Abandoning hospitals
  - Control movement between villages
  - Isolating the sick
  - Survivors as caregivers
  - Modified burial practices

Result: outbreaks being actively controlled by the time international teams arrived

Changes in Mano River countries (Côte d'Ivoire, Guinea, Liberia and Sierra Leone):

• People are learning and adapting

- Ebola is slowing in previously hard hit areas
- Village or chiefdom quarantines
- Neighbourhood watch/task force (n.b. remilitarisation)
- o 'False burials', reparation ceremonies
- Protective measures in home care plastic bags, one on one care
- Suspension of initiation
- Reduced participation in burials

# Ebola, Culture and Politics: The anthropology of an emerging disease. Chapter 7: Outbreak Control.

Hewlet BS & Hewlett BL (eds). 2008. Thomson Higher Education. (Not available online)

What beliefs and practices in the community enhance ebola control efforts:

- Local people have indigenous concepts and cultural models for epidemic illnesses
- Shifts in cultural models to explain Ebola are common, and criteria may exist for distinguishing sorcery for epidemic illnesses
- Local people have indigenous protocols and cultural behaviours to control epidemics
- Local people believe that children are particularly vulnerable to epidemic diseases; children easily learn about contagious disease
- Local people encourage harmony in the family during outbreaks
- Local people are ready and willing to help with control efforts

What beliefs and practices within the community are linked to Ebola control efforts but are neither health enhancing nor health lowering?

Aid efforts should be aware of the following activities to develop community trust but do not need to encourage or discourage the activities.

- Use of indigenous herbs
- Therapy managing group (family members making decisions about the care of a patient
- Activities to chase away spirits associated with the epidemic

What beliefs and practices in the community enhance control efforts in some contexts and amplify the outbreak in other contexts:

- Healers
  - In Congo healers requested gloves and bleach and wanted to help with control efforts but promoted sorcery explanations.
  - International and national teams should provide education to healers, provide protective gear and encourage them to refer cases. Agencies should not incorporate healers into control efforts where sorcery is common.
- Fear and the rapid spread of information
- Regular lived experience with deadly infectious and parasitic diseases

# Ebola: the power of behaviour change

Sebastian Funk, Gwenan M. Knight & Vincent A. A. Jansen Sebastian Funk, Gwenan M. Knight & Vincent A. A. Jansen. Nature 515, 492 (27 November 2014) http://www.nature.com/nature/journal/v515/n7528/full/515492b.html

Without including social, cultural and behavioural responses to the Ebola epidemic, models may overestimate outbreak size.

Behavioural response, triggered by an epidemic, can slow down or even stop virus transmission. Indeed, altered cultural perception in response to the disease enabled people's behaviour to change in ways that helped to contain outbreaks in the past.

Reports from Foya in Liberia indicate that the outbreak there is now in decline. A local information campaign to change funeral practices and other behaviours seems to have paid off.

More aid and more personnel are urgently needed, but so is the involvement of local communities and the provision of information that can help to contain this epidemic.

# The spread of awareness and its impact on epidemic outbreaks

Funka S, Gilada E, Watkins C & Jansen V. 2009. PNAS. 106 (16) http://www.pnas.org/content/106/16/6872

When a disease breaks out in a human population, changes in behaviour in response to the outbreak can alter the progression of the infectious agent. In particular, people aware of a disease in their proximity can take measures to reduce their susceptibility. Even if no centralized information is provided about the presence of a disease, such awareness can arise through first-hand observation and word of mouth. To understand the effects this can have on the spread of a disease, we formulate and analyse a mathematical model for the spread of awareness in a host population, and then link this to an epidemiological model by having more informed hosts reduce their susceptibility. We find that, in a well-mixed population, this can result in a lower size of the outbreak, but does not affect the epidemic threshold. If, however, the behavioural response is treated as a local effect arising in the proximity of an outbreak, it can completely stop a disease from spreading, although only if the infection rate is below a threshold. We show that the impact of locally spreading awareness is amplified if the social network of potential infection events and the network over which individuals communicate overlap, especially so if the networks have a high level of clustering. These findings suggest that care needs to be taken both in the interpretation of disease parameters, as well as in the prediction of the fate of future outbreaks.

# Ebola: limitations of correcting misinformation

Chandler C et al. 2014. The Lancet

This comment piece focuses on communication and social mobilisation strategies that are designed to raise awareness about Ebola virus disease and the risk factors for its transmission. The authors argue that these strategies are central elements in the response to the current Ebola outbreak in west Africa. The aim of the strategies must be to change risky behaviour related to traditional practices and misinformation. Providing biomedical information alone can be ineffective. Communicating knowledge may be insufficient to induce behavioural changes in practice, usually because of people's other priorities. The way people complete activities including caring for the sick and deal with death may override health concerns. Such concerns must not be disregarded. A flexible approach is required. Trying to shift people's framings away from traditional beliefs is embedded in the public health view of biomedicine as the only valid way to understand and respond to illness. This may not be successful. Safer practices need to be adopted without changing people's core beliefs. Protocols for behavioural change are typically developed at national or international levels rather than collaboratively with the people who are expected to change their behaviour. Standardised approaches discourage adaptation, prohibits engagement with local social realities, and ignores how people will interpret public health messages according to specific local political and social circumstances. Engagement across communities with flexible protocols that communicate problems, request help in developing local solutions, and enable their implementation are likely to be more effective in changing high risk practices than

standardised approaches. Using standardised advice for non-standardised situations may not be effective. Action and advice must be locally practical, socially acceptable, as well as epidemiologically appropriate.

Ebola, Emerging: The Limitations of Culturalist Discourses in Epidemiology Jones J. 2011. The Journal of Global Health, 1-6 <u>http://www.ghjournal.org/ebola-emerging-the-limitations-of-culturalist-discourses-in-</u> epidemiology/

Published in 2011, this paper offers a critique of the culturalist epidemiology that dominates the discourse of Ebola in both popular and international health spheres. Ebola has been exoticised, associated with "traditional" practices, local customs, and cultural "beliefs" and insinuated to be the result of African ignorance and backwardness. Indeed, reified culture is reconfigured into a "risk-factor." Accounts of the disease paint African culture as an obstacle to prevention and epidemic control efforts, at times even linking the eruption of the disease to practices such as burial traditions or consumption of bushmeat. But this emphasis is misleading; the assumption of African "otherness," rather than evidence, epidemiological or otherwise, underpins dominant culturalist logics that "beliefs" motivate behaviors which increase the likelihood of Ebola's emergence and spread. Conspicuously absent from both popular and official rhetoric has been attention to larger structural determinants of the course of Ebola epidemics. Yet global forces condition the emergence of Ebola far more than culture does. Inequality and inadequate provision of healthcare, entrenched and exacerbated by a legacy of colonialism, superpower geopolitics, and developmental neoliberalism, are responsible for much of Ebola's spread. Certainly, structural force alone cannot account for the destruction Ebola has wreaked on the lives of victims and their families. Culture does matter. But the focus on culture comes at the expense of attention to sociopolitical and economic structures, obscuring the reality that global forces affect epidemics in Africa. This paper seeks to map the discursive contours of Ebola's emergence, contextualise these trends within a larger debate about the role of anthropology in epidemiology, and question the simplistic link between culture and Ebola through a critical examination of structural-level forces.

# How social, food, and healthcare seeking behaviours are shaping the circulation of Ebola differently in affected countries, following patterns of resilience and fragility. Richard P et al. (unpublished)

In each country, Ebola seems to be following specific movements through the population that are distinctly associated with (a) food security, (b) social security and relations (including customary practices like funerals), and (c) historical relations between the population and the government. But in each country, the patterns are different. Proposed low-cost interventions that integrate local case reporting with distributed communications channels flowing to centralised data collection systems can make a difference. Such a system might look like this:

- Introduce the mass distribution of international health identification cards with distinct alpha-numeric numbers for each individual person. Engage traditional leaders, town chiefs, mayors, religious leaders, and paramount chiefs to assume responsibility for conducting a census that links all individuals within communities to specific health iD numbers. Make community leaders responsible for reporting local deaths (all local deaths) through a messenger system (young boys on motorcycles, for example) that communicates all mortalities on a daily or semi-weekly basis with central epidemiological monitoring systems.
- The messenger system could interact with a rapid communications system that would need to be constructed across the region. This can be done so easily using existing, widespread, and easy-to-use military-grade two-way communications systems, which

can be installed widely, quickly, and cheaply by existing US AFRICOM command, and can be operated with little technical support. With four to six systems in place in each district or county across the region in all three countries (and a greater concentration in dense urban areas), plus the removal of low-cost barriers (like phone cards, fuel for motorcycles, or costs of transport) cases and fatalities could be readily reported upstream to an Ebola-chain-of-Command that engages in case fatality monitoring and tracking. This would make it possible to geographically identify potential emerging and current Ebola hot spots across the region, and magnify our understanding of urban/rural and regional circulation of the virus.

- Although it would be impossible to identify which mortalities reported were Ebolarelated mortalities, this proposed case reporting mechanism could make it possible for epidemiologists to track all patterns of mortality in real time (even mores if the health ID system were tied to household residence), and thereby remotely identify previously undetected "hot spot" areas with the rapid concentration of fatalities, which could then be visited for retroactive identification. This would not help those who had died, but it could expand the network of support around communities and families that are currently infected, or at risk of infection.
- By bringing together local community leadership with a more robust system of epidemiological tracking, and by identifying currently unrecognized or emerging "Ebola hot spots" across the region and patterns of social circulation, it will be more possible to establish community-based quarantine systems, restrict mobility, and change local cultural practices for a limited period of time.

# The flow of money at the community level

Bedford J. 2014. UNMEER https://www.tecom.usmc.mil/caocl/EbolaResponse/Reference%20Materials/The%20flow%20 of%20money%20at%20the%20community%20level.pdf

This brief summarises some key considerations about the flow and control of money in relation to the Ebola response. These are general considerations that are broadly relevant, but further investigation into local specificities is required.

# Mobilising informal health workers for the Ebola response: potential and programme considerations

Wilkinson A et al. 2014. Briefing Note. On behalf of the Ebola Response Anthropology Platform

http://www.ebola-anthropology.net/key\_messages/mobilising-informal-health-workers-for-theebola-response-potential-and-programme-considerations

Informal health workers are important care providers in the region and continue to be so during the current Ebola Virus Disease (EVD) outbreak. Many are well respected and trusted members of the community who can mobilise large numbers of people for a particular activity and lend legitimacy to a particular programme. The key points are as follows:

- Informal health workers are important care providers in the region and continue to be so during the current Ebola Virus Disease (EVD) outbreak. Many are well respected and trusted members of the community who can mobilise large numbers of people for a particular activity and lend legitimacy to a particular programme.
- 2. Informal health workers are markedly heterogeneous in terms of the degree to which they draw on biomedical and traditional treatment beliefs, their perceived legitimacy in their communities, the strength of their ties with local societies and institutions, and the extent to which they are willing to support external initiatives. Adopting a flexible approach that is adaptable to each local context is therefore crucial to programmes seeking to engage with informal health providers.

- 3. There is existing experience of successfully partnering with informal health workers in the region, both before and during the current outbreak, that can be drawn on to inform such programmes. Potential benefits of such partnerships include reducing the risk of transmission during the provision of informal care, improving the treatment of EVD and other major illnesses, and supporting home and community care interventions through their social capital, networks and local institutional ties.
- 4. The informal health sector in Sierra Leone encompasses a number of different kinds of practitioners, including formal health sector workers working informally in their communities, unlicensed drug sellers, herbalists, religious therapies, traditional birth attendants (TBAs), and traditional healers using knowledge passed through their families or linked to secret societies.
- 5. Medical doctors are generally highly respected, and people particularly in urban areas are normally keen to seek medical attention at pharmacies and hospitals if resources permit. However, there is now a widespread distrust of hospitals and Ebola treatment facilities. People fear being wrongly diagnosed with Ebola, and either harmed by the treatment process or worry that they will catch Ebola in hospital. In part this attitude stems from a distrust of the motivations and the capabilities of the government during the crisis, who many feel willingly benefit at the expense of ordinary people.
- 6. There is a general willingness for individuals to adopt multiple methods in regard to care and wellbeing. Medical assistance often goes hand in hand with prayer and religious practices, and consultations with herbalists and other traditional healers.
- 7. All health practitioners draw on varying degrees of biomedical and traditional understandings to interpret causes of illnesses and appropriate treatments. There is evidence that, at least in some areas of the affected region, most traditional healers believe that EVD exists. They also, however, may perceive that sorcerers may take advantage of the outbreak in order to conceal their attacks on victims.
- 8. The legitimacy of both formal and informal health workers comes from their renown in demonstrating skill and compassion in caring for people in the context of what is appropriate for their position in society and their ties to the community or other institutions in which they are embedded. People may well travel far to consult with practitioners of particular renown. Additional important factors in seeking care from informal rather than formal institutions include more flexible payment mechanisms and geographical proximity.
- 9. However, informal health workers are not universally respected. While many informal health providers are deeply respected, others are less well trusted and may be perceived to be profiting from people's poor health and not have the best interests of the community at heart. Being closely embedded into the communities where they practice may mean that informal health providers are subject to local politics and economies that have implications for their ability and willingness to engage with external initiatives.
- 10. Informal health providers continue to play an active role in caring for sick people in the region. There are a number of reasons for this role to have increased during the outbreak: increased closures of formal health institutions; early health education messages reinforcing the lack of effective biomedical treatment; and in the case of Sierra Leone, registered pharmacies being officially banned from operating. Despite the latter, many continue to buy medication from local pharmacies but are forced to so in underhand ways.
- 11. Some informal care acts are therefore likely to be contributing to the transmission of EVD, with evidence for example that practitioners of particular renown have previously acted as transmission hubs. Engaging with care providers can potentially reduce the risk of their practices.
- 12. The legitimacy of informal health workers as trusted health providers offers an opportunity to provide EVD or other treatment through them and their networks. There is experience of providing quality treatment through the informal sector in

Sierra Leone, for example the Global Malaria Fund has used Traditional Birth Attendants to provide anti-malaria and anti-parasite treatment.

- 13. Informal health workers may have extremely strong social ties and capital that has the potential to be mobilised and linked in to the response. Secret societies in particular are one of the most trusted local institutions and can, if they wish, mobilise hundreds of people to support a particular activity. These networks can be used to improve surveillance of cases, disseminate knowledge or build structures and provide the support needed for home and community care of EVD patients.
- 14. Given the heterogeneity of informal health workers, their position in different local communities and the potential for friction between different providers and community members, a key approach to engagement will be to take time to identify who the well-known and trusted providers are in a particular locality, who they work with and what networks or associations they are part of. Options for collaboration across a network include two traditional healer associations with their headquarters in Freetown.
- 15. A number of organisations have previously run programmes engaging with informal sector workers, including for TBAs alone: Marie Stopes ongoing family planning campaign (TBA volunteers inform local women about contraception), the Global Malaria Fund as mentioned above, CARE (TBAs recruited as social activists), and UNFPA (teams of TBAs boost community awareness about sexual and reproductive health, maternal mortality and gender violence). During this outbreak, WHO have trained traditional healers in Guéckédou, Guinea on signs of EVD and appropriate referral to an Ebola Treatment Unit.
- 16. The feasibility and extent to which informal health workers will be willing to help will depend on the particular initiative proposed and the extent to which their beliefs and concerns are respected and taken into account. Showing support for a particular initiative may pose a very real threat to their own legitimacy and position in society, therefore there is the potential to disrupt some of the few still-functioning care networks in the region.
- 17. It is particularly important to avoid reinforcing a dichotomy between formal and informal modes of care by portraying both as complementary. Despite the above examples of successful partnerships, there is considerable tension between many formal and informal practitioners. Programmes engaging with the informal sector would need to be sensitive to such relationships.
- 18. It is likely that there will be other sensitivities particular to a given kind of practitioner in a given locality that need to be understood and taken into account. For example, TBAs have particular sensitivities about gender and secret knowledge.

#### 8. Illustrations

# Figure 1: Monrovia Community Leaders' Representation of Optimal Community Based Care August-September 2014



Source: Alane Abramowitz S et al. (date unknown)

# 9. Additional information

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