

Helpdesk Report: Ebola- local beliefs and behaviour change

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Query: What are 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 nature of burials) and can inform effective behaviour change interventions for preventing Ebola in Sierra Leone?

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1. Overview

⁶The Ebola epidemic ravaging parts of West Africa is the most severe acute public health emergency seen in modern times. Never before in recorded history has a biosafety level four pathogen infected so many people so quickly, over such a broad geographical area, for so long' (Margaret Chan, 26th September 2014, WHO).

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 (Hewlett and Hewlett 2008).

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 (Chippaux 2014). 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. For example, in Chippaux (2014) he gives a summary of some effective policy adaptations, including that 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 (Chippaux 2014).

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 (Wilkinson, 2014, STEPS blog). 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.

Disease overview

Ebola haemorrhagic fever is a virulent viral disease causing death in 50-90 percent of clinically diagnosed cases (Hewlett and Hewlett 2008). As a comparison, the rate for the SARS outbreak was 9.6 percent (WHO, 2004). The virus family Filoviridae includes 3 genera, of which Ebolavirus is one. There are 5 species that have been identified and the virus causing the 2014 West African outbreak belongs to the Zaire species (WHO, 2014). The incubation period is two- 21 days, with the initial onset being characterised by sudden fever, weakness, muscle pain and headache. This is followed by a sore throat, vomiting, diarrhea, a rash and abdominal and thorax pain. The final stage is characterised by hiccups, delirium and bleeding under the skin and from the mouth, nose, intestines and other openings, although haemmorhaging generally occurs in less than 50 percent of cases. It is extremely difficult to diagnose in the early stages as its symptoms are common to other diseases e.g. malaria (Hewlett and Hewlett 2008).

It is thought that fruit bats of the Pteropodidae family are natural Ebola virus hosts. Ebola is introduced into the human population through close contact with the bodily fluids of infected animals. Ebola then spreads through human-to-human transmission via direct contact (through broken skin or mucous membranes) with the blood, secretions, organs or other bodily fluids of infected people, and with surfaces and materials contaminated with these fluids. People remain infectious as long as their blood and body fluids, including semen and breast milk, contain the virus. Men who have recovered from the disease can still transmit the virus through their semen for up to 7 weeks after recovery from illness (WHO, 2014).

Coverage has focused on the 'global outbreak narrative', seen around so many other emerging infectious diseases, in which a disease 'out of Africa' threatens a world of mobile people and microbes. However, Ebola is of course a set of personal tragedies, losing loved ones, and a tragedy for a social fabric where people now fear to hug, to shake hands, to make love – and where doing the social and moral good of caring well for the sick and the dead well brings likely sickness and death. Beyond this, Ebola presages a set of livelihood tragedies as food and trade routes break down (Leach 2014).

2. Unsafe burial

The greatest numbers of Ebola virus disease (EVD) cases to date in Sierra Leone are found in villages in Mende-speaking areas. Funerals are known to be a factor in communicating EVD. The corpse is often still highly infectious. Cases have been reported in which the virus has been transmitted to mourners at funerals and especially to those involved in preparing the body for burial. Thus, it is important to understand Mende village burial practices (Richards et al, 2014 <u>http://www.culanth.org/fieldsights/590-village-funerals-and-the-spread-of-ebola-virus-disease</u>), and burial practices in Sierra Leone generally. However, such practices are not standardised, are likely to change as social responses to Ebola evolve, and therefore need to be discussed on a locality by locality basis (Fairhead, 2014, briefing). The region has many religions, Christian, Muslim and the ancient indigenous religious practices. Burial should respectful of all. Fairhead's paper, *The significance of death, funerals and the after-life in Ebola-hit Sierra Leone, Guinea and Liberia: Anthropological insights into infection and social resistance* goes into this in more detail than is possible here.

Understanding local beliefs around death

Fairhead, 2014 describes local beliefs around death; 'for many, mortuary practices are orchestrated to enable the dead person to accede to the 'village of the ancestors' where they reunite with the dead and live a very similar life to those on earth and continue to participate in affairs on earth. How the person has lived on earth does not shape their destiny there. This is determined instead by the accomplishment (or not) by those living of the mortuary requirements that are due them. If the correct treatments and sacrifices are not made, the spirit might not even attain the village of the dead, and will be condemned instead to wander eternally, and return to torment their family. This is to be feared, as the angry spirit will throw spells on their descendants, send illnesses, make pregnant women abort, or make them give birth to monsters. This is why people are so concerned by the proper conduct of funerals, and seek to die among respectful friends and family. To die of Ebola is one thing, but to be deprived of an afterlife is quite another. Even recently, seriously ill patients or their relatives who manage their treatment are likely to give higher priority to communal feasting and secret society fees than to expenditure for clinical consultation and drugs. People desire strongly to be buried in their own community so that they can rejoin their ancestors in the 'village of the dead', and will go to great efforts not be left to wander eternally the lonely stranger-dead. Unceremonious burials near Ebola Treatment Centres that are outside of villages may well echo the burials of the sorcerers, robbers and strangers, so it is not surprising that people may be hesitant to die there' (Fairhead, 2014).

More details on a particular region can be found in MacCormack's paper; 'people living in the Sherbro coastal area of Sierra Lone have a social organisation based upon descent from named ancestors. Ancestors, the living and those not yet born constitute a great chain of This continuum of existence is punctuated by, and made discontinuous by rites of beina. passage (birth, puberty, death). Dying is a period of ambiguity in which a person is still among the living, but babbles of the past, a sign that he or she is in the process of becoming an ancestor. Senility is positively interpreted as a sign that the person has begun to slip across into that aspect of being (this could be important for interpretation of Ebola symptoms too). Ancestors are the ultimate source of blessings and misfortune so the dying are treated with great consideration. The ambiguity of this stage is resolved through rituals which 'carry' the immediate deceased through this inbetween stage and places them in a category of ancestors. Until this is done, the period of ambiguity is perceived by the community as a period of danger. Post mortems of internal organs are also routinely done by Poro (the men's secret society) to look for signs of the true character of the deceased. These have a bearing of the specific content of the death rites. This is based on 15 years of field work in coastal Sierra Leone and more detail can be found in the full paper' (MacCormack 1985).

The importance of burial practices cannot be underestimated as they are strictly controlled by the male and female societies (known as 'secret societies' in English) who are central to local and regional politics. Medical teams wishing to prevent traditional burials will likely be intervening in domains of power and 'secret' knowledge that lie at the heart of the socio-political fabric which society officials control (Wilkinson, 2014, STEPS blog). A proper burial, where the family demonstrate respect for the deceased's spirit, is a key element of African life and funerals have become a key source of Ebola infection in the region. The spirit continues to stay close to the family and if not respected can bring harm, illness and misfortune (Hewlett and Hewlett 2008). Mourners may contract the disease by touching the corpse to express sympathy or say farewell or by coming into contact with those who have nursed an Ebola patient. In other cases, it is the movement of the corpse between villages that is likely to pose a transmission risk to neighboring communities. This risk might occur when a woman relocated upon marriage to her husband's village dies, and needs to be interred at home (Richards et al, 2014 http://www.culanth.org/fieldsights/590-village-funerals-and-the-spread-of-ebola-virus-disease).

Rural burial practices and preparation of bodies for burial in Sierra Leone Aspects of burial and funeral practices that can amplify outbreaks are underlined

Specific issues in the case of Sierra Leone are that 'there is a gendered dimension to death and funeral rituals because of rights in potential offspring, the practice of polygamy, and levirate (a man's wives being "inherited" by his surviving brothers at his death), which makes what happens when a man dies very different to what happens when a woman dies. Things are much more dangerous when a man dies in Mende-speaking Sierra Leone, because part of his wives' mourning involves <u>smearing her head and face with mud formed by the runoff</u> <u>water from his body's washing. A similar practice was not seen with widowed men</u>' (Mariane Ferme, email communication, 2014, referring to her 2001 book, referenced below).

"<u>Bodies are washed and touched</u> (though not much in my experience: body washing was a specialised occupation of only 3 or so elders in the community, and was done out of sight of the rest of the community, and by the time the body was seen again by the general population it was wrapped in cloth, with only the eyes showing. So even if that body was touched, it was through clean cloth. No kissing--people don't kiss each other when they are alive, they don't start doing so with a body. In my opinion, it would be fairly easy to persuade people not to touch a body, or to touch it less than is normally done (Ferme, email communication, 2014).

Only a particular kind of divination session, performed when there was some doubt as to whether the deceased may have been <u>a witch</u>, involved a ritual specialist touching the body' (Mariane Ferme, email communication, 2014). As with disease, there are multiple kinds and causes of death. Certain circumstances – such as sudden death or that of a pregnant woman – raise suspicion. 'Witchcraft' is the most frequently discussed but this confuses some distinct phenomena including malicious spirits, bad intent by sorcerers, and inappropriate behaviour. If a death is blamed on 'witchcraft' it is necessary to establish which of these three is thought to be at work as they will be dealt with differently. Such deaths may require special practices and again secret knowledge is likely to be important. This may be an additional reason why funerals are proving a flashpoint in this epidemic. It is possible that by not allowing the secret societies to carry out the appropriate cleansing after unusual deaths that medical teams are perceived to be making the situation worse (Wilkinson, 2014, STEPS blog).

However, Fairhead, 2014 described touching in more detail, and slightly differently, showing there are many traditions, not just one formula, as mentioned earlier. 'There are several aspects of mortuary practices in which people touch bodies. The first concern washing the body. There are other important reasons for touching a body. First, the deceased's eyes need to be closed, usually by a brother. Second, in the privacy of a hut, the corpse should be

washed, sometimes also oiled (with palm oil), and then dressed well. <u>Usually men will wash</u> and prepare men, and women, women. For several reasons, the body will be washed twice, first when initially clothed or wrapped in a fine cloth, and then when re-clothed for burial (perhaps in cheaper material). <u>This rewrapping and the fate of the recycled cloth will both be</u> sources of funeral-related infection' (Fairhead, 2014).

'A second set of reasons for touching the body concern divinatory practices. During some mortuary ceremonies, it is important to ascertain whether (a) the dead person was themselves a sorcerer - all people can be suspected to have been a sorcerer, and recent misfortunes might be attributed to them; or (b) whether the dead person was killed by a sorcerer. The more important the person, the more likely someone might be blamed. Modes of divination vary. In one version used historically (and potentially, today) the dead body (or as a substitute of the clothes, hair and fingernails of the deceased) is paraded on a head-held stretcher around the village so the deceased spirit can speak through a living medium to name the sorcerer or admit themselves to be one. In another version, the spleen (or liver) of the body is removed and put in water, and if it sinks, the person was a sorcerer. The use of bodies in such divination to discover the cause of death has been noted as one reason for infection in the Ebola crisis. This is not a tradition destined 'to die out'. It is very important to identify witches prior to their burial, as a witch must be buried in a special way "to render the spirit innocuous, or they will continue after their death to cause illness, crop failures and other misfortune." Those who do not attend funerals, or who mourn insufficiently might well be suspected of sorcery, which accounts in part for the high attendance at funerals' (Fairhead 2014).

'A third reason for touching the body concerns the 'initiation' of youth. The deaths of the young who have not yet been initiated are usually relatively small affairs – they are not yet full people. In some locations, however, on the death of an uninitiated girl, her body is washed, rubbed with shea butter or palm oil and dressed in her best clothes. Her hair will be carefully plaited and every wish she had expressed complied with. Things become more elaborate if the date of her initiation was already fixed, so the dead girl will arrive at the dead with the social status of an adult. The old women proficient in excision (i.e. 'Female Genital Mutilation' will be called and the dead body initiated into sexual adulthood in this way. Perhaps if the girl was engaged, the groom would have to 'marry' the corpse, and spend a night in its company or risk the dead girls' wrath.' (Fairhead, 2014).

'Rural Sierra Leoneans are also familiar with people sometimes reviving after apparent death, and <u>bodily contact with the deceased around the time of death helps confirm that the person</u> <u>really has died</u>. This contact is thus not as strange as some outsiders appear to find it (Fairhead, 2014, briefing). There are compelling reasons to attend the house of the dead and the eventual internment. First, there is a need to express empathy for the bereaved. Second, there are social obligations to be discharged (e.g. to kin or affines). Third, absence might create suspicion (deaths are often attributed to malice rather than misfortune) (Fairhead, 2014, briefing). Where someone should be buried is also important, those who are local to the village should be buried there and strangers (e.g. visiting health workers) should be buried outside the village' (Fairhead, 2014).

'In some regions, the body of the first child to die from any couple is buried in a very different way and in a special location. Their death is effectively denied as their body is returned 'to the land' effectively as the family's personal sacrifice to the land spirit. This person will thus not re-join the family ancestors. They are lightly buried (or simply thrown without ceremony) in a special wooded area on the village margins. They are washed with a special decoction and buried naked, wrapped only in leaves of *Newbouldia Levis*, and carried by men if male, and by women if female. Sometimes all the 'bad deaths' (of strangers, those struck by lightning, lepers etc.) are also buried among these "first dead" (effectively becoming sacrifices to the land). A confessed sorcerer can be buried in the mud near a pond or river – never in the village – , upside down and naked. Whether any burial is 'East / West' or 'North / South' and

which is the head end is significant, as is whether the burial of a person is on one side or the other. Exactly what the significance is needs to be discerned for each location' (Fairhead, 2014)

Gender issues

'Typically, a third to a half of all married women in a Mende village have been born in another settlement, generally a neighboring village, though some come from further afield. In Mende settlements, persons living outside their village of birth are known as *hota* (stranger). Natives of the settlement are *tali* (town people). Female marriage partners from outside the village are also classified as hota. A female hota in an incomplete marriage is liable to be taken to the <u>village of her lineage for burial</u>. Marriage for Mende villagers is a process, not a state. A relationship begins upon agreement that certain gifts and services will be provided for the parents and family of the woman by the husband in recognition of that lineage's gift of a bride' (Richards et al, 2014 <u>http://www.culanth.org/fieldsights/590-village-funerals-and-the-spread-of-ebola-virus-disease</u>).

'In a recent study (May–June 2014) of three villages in Kamajei chiefdom (Moyamba District) data were collected on 79 current marriage partnerships. This was a random sample of about one third of all marriages in the three settlements. The female partner was hota (i.e. came from outside the village) in 62.2 percent of cases (averaged over the three villages). In only 15.9 percent of cases was the marriage recognised to be complete. The figure was smaller for tali marriages (8.8 percent)'. (Richards et al, 2014).

'The hota partners of incomplete marriages are of special significance to the spread of Ebola, since in the case that the woman dies the husband will be expected to travel to her home village and make a settlement of outstanding marriage promises before he is given permission by the family to bury his wife's corpse. Burial will generally then be done in the woman's village' (Richards et al, 2014).

A behaviour change which may be possible is: 'In certain regions (e.g. Sherbro) women may be conveyed to their natal homes to be buried. Importantly, however, when a death occurs away from home and the body could not be brought back, the stone (or similar) can be taken from the actual tomb and brought to the native village so the deceased can be integrated with their ancestors. Such a tradition enables one to avoid moving actual bodies home, and such a ritual might be significant in addressing properly the burial of some Ebola victims away from home. A similar item for a deceased woman might be placed on the altar of the women's cult' (Fairhead, 2014).

One area where culture affects decision making regarding going near a corpse is wife inheritance. In Ferme's book, The Underneath of Things, wife inheritance (po nyahanga) is described, where widows marry a dead man's brother after a 40 day mourning period (http://books.google.co.uk/books?id=hHfy4poWQw8C&printsec=frontcover#v=onepage&q&f= false). 'This was more common in Kpuawala, where the author is writing about, when the widow is part of a large household comprising resident adult sons and their families, who were an attractive labour source and dependents for aging male relatives of the deceased. She gives an example of an elderly widow who was intensely courted by surviving brothers. As part of this process, 40 days after the death soil from the place where the dead husband was washed is collected, mixed with water in a hole and the widow, whose head had been kept shaved brought her face and mouth down to the hole and initiates a ceremony where she addresses her husband and says now he is dead they are no longer married, his spirit should stop roaming close to her and not be jealous and his children are left to her (more details on page 94 of the book), mud is smeared on the widow's body and an area set up only to be entered by other widows. A similar thing happened with widowers, but there was no link to initiation and there were other rituals which did not involve the dirt which had been

in contact with the wife's body. New spouses who are elderly often do not move to physically live together. This revisiting of the location of a corpse may be significant'.

Urban burial practices in Sierra Leone (Lipton 2014)

⁶Funeral practices in Freetown are varied with differences between typical Muslim and Christian practices. Muslims typically bury the body the same day, or the day after, the death, whereas Christians might wait for up to several weeks while arrangements are made. Muslims normally bury bodies in a shroud, whereas Christians use a coffin. The bodies are typically prepared for burial (washed) by family members.

Funerals typically consist of a vigil (for Christians) the night before the burial, followed by a religious service in a Church or Mosque during the day, then a parade through the streets to a public cemetery. There are often gatherings in the subsequent days, where food is cooked and eaten communally. After 40 days there is another significant ceremony. Some residents of Freetown are also buried in their family villages upcountry (most residents of Freetown identify a village as their 'home' village).

The physical burying work in many cemeteries in Freetown is performed by undertakers who are informally attached to cemeteries. Payment is made through a collection after the ceremony.

Funerals are important social occasions, which people value attending highly and travel long distances for at significant personal expense. They facilitate acute expressions of grief during the ceremony surrounded by more celebratory elements.

Since the Ebola outbreak many in Freetown have been cautious about attending funerals because of the health risk. While some are resistant to the authorities performing burials, others have abandoned bodies in the street, in part to avoid their households being quarantined or infected'.

Examples from other cultures

Examples from the Congo showed that burial and funeral practices were important to the ways in which Ebola has been transmitted and showed how practices could be modified to prevent disease transmission (Hewlett and Hewlett 2008 p.78- How can burial and funeral practices be modified to decrease Ebola transmission?). In most parts of Africa, shortly after the person dies, the body is washed and dressed in a favourite outfit. The gender of the person who washes the body is the same as the person who dies, except for children which can be washed by either. Often people are placed on a bed for twenty-four hours, while family members kiss, hug and lay next to their loved one, wrapping the deceased in a sheet shortly before burial, performing communal washing of hands shortly after burial and then social activities such as dancing or sleeping together occur for several days after the burial.

'An analysis of media reports of resistance also reveals that concerns around death and burial have led to several forms of resistance to Ebola response teams. The most commonly reported form of resistance concerns villagers repelling intrusion (blocking roads and cutting bridges), stoning intruders and their vehicles. In the worst case in the Guinean Sous-Prefecture of Womey, villagers killed nine intruders, among them three senior doctors, three journalists, a pastor and the town's health worker, but there have been lesser attacks both in rural and in urban areas' (Fairhead 2014).

How this affects decision making and can inform effective behaviour change interventions

'The bottom line is that even with rituals, people are more flexible than they are normally given credit for. During the war in Sierra Leone, many ordinary rituals, from initiations to funerals, were interrupted, and people either performed "place-holder" gestures promising a fuller treatment when the war made it possible, or skipped them altogether until it was safe to hold these ceremonies. I don't see why the same would not happen with Ebola. I do think there would be serious resistance to cremation in Sierra Leone, and have no idea why this solution was introduced in Liberia' (Mariane Ferme, email communication, 2014).

This is also confirmed by James Fairhead, in his paper. 'Ebola is not the only factor to cause deviation from "correct" burial procedure. Security concerns were a disruptive factor during the civil war, for example. A person may die in an accident or far from home and have to be buried at once. There are established procedures to compensate dereliction and to assuage guilt in such cases. Matters might be corrected by compensating rituals intended to guard against the anger of the dead' (Fairhead, 2014).

'Some practical ways that local people can be given advice are: More than 80 percent of all marriages in which the female partner comes from another village are incomplete in the three Kpa-Mende villages surveyed. This figure calibrates the substantial potential for mourners and corpses to move between villages for burial when female frontline caregivers are affected by EVD. Villagers need advice and equipment to ensure safe burials of Ebola victims. If the risks of delayed burial and the movement of corpses are well explained, there is every reason to expect that practical adjustments of funeral practices consistent with Ebola control will be locally implemented' (Richards et al, 2014 http://www.culanth.org/fieldsights/590-village-funerals-and-the-spread-of-ebola-virus-disease).

Practical concern at burials is expressed by placing a gift of money on the ground. This "non contact" giving has clear cultural salience, and the idiomatic implications might be explored to cover other "non contact" forms of expression of concern for the welfare of the bereaved caregiver (e.g. provision of food, clean clothing, warm water). Here again, the ideas (and cultural creativity) of villagers need to be engaged. Preparation of bodies for burial is also an important topic. In general, corpses are cleaned and oiled for burial. From the perspective of disease transmission it would be ideal to avoid all such procedures, but they carry strong cultural significance and elimination is unlikely in villages. An alternative is to look to ways of making body preparation as safe as possible, e.g. through use of hot water, chlorine, and protective items such as rubber gloves. The water or mud from body washing is sometimes used for other purposes, such as anointing widows to help free them (when the mud is washed off) from the dead husband's spirit. Villagers may be able to suggest alternative means to achieve such ends without incurring the risk of EVD transmission. Risky "optional" procedures should be flagged for discussion, with a view to discouragement, such as the sprinkling of water used to wash the corpse of a dead Islamic teacher said to have spread EVD among children in his charge' (Fairhead, 2014).

How can practices be influenced by external organisations in Sierra Leone? (Lipton 2014)

'Monetary (and other) compensation could play a major role in influencing care and burial practices. During the crisis many people's income and welfare has been severely affected. Many feel aggrieved that they do not see evidence of the aid money that they hear about. Compensation (even if relatively small) could allow people to live in a more dignified way, and help people support their families and neighbours, which might encourage and rationalise adjustments to practices and attitudes in locally meaningful ways' (Lipton 2014).

'If burials are performed by the government (or other authorities), families could still be consulted and included. For example, the bodies could be buried in local cemeteries (alongside other family members). This could allow for future gatherings and ceremonies at

the gravesite. The authorities could also provide some funds/food for the family to cook and eat communally, which is an important ceremonial feature of funerals' (Lipton 2014).

'Religious channels can be effective avenues to influence care and burial practices. Prayer has played a major role in people's response to the Ebola outbreak. Many conceive of Ebola in religious terms, such as 'God's punishment for corruption', which requires a religious response. However, there is some flexibility about what this can entail. Religious leaders are highly respected members of society, including between Muslims and Christians, who have a broadly harmonious relationship in Sierra Leone. Weekly sermons at Mosques (Friday) and Church (Sunday) are well attended, and preachers are often well educated and open-minded, and regularly deal with contemporary issues and wellbeing in their teaching and sermons. Additionally, people regularly make major lifestyle adjustments for religious reasons, such as weeks/months of fasting (for both Christians and Muslims) and abstinence from sexual activity' (Lipton 2014).

'Trust of authorities is an important factor. While many people are proud of being law-abiding and respectful to authorities, there is a widespread mistrust of the motivations of the police and army, who are often badly paid and gain an income through bribes and fines. Some are worried and puzzled at the arrival of the UK military. However, people generally conceive of the motivations of international organisations and NGOs as being benevolent, even if they acknowledge that things become messy and political on the ground. Doctors and nurses are also respected' (Lipton 2014).

'Knowledge has spread in rural communities of the risks posed by funerals for transmission of EVD. More work is needed to document these local understandings, and assess what behaviour changes they might have induced. Clearly, local ideas and practices conducive to risk reduction should be encouraged' (Fairhead 2014).

In addition, if you are looking beyond the local beliefs to how to perform safer burial practices, something we have discussed is the challenge that even if a front-line worker is able to communicate well with the public, and can listen to their concerns, a key challenge can be to be in a position to respond appropriately. This may be due to either direct demands to follow a protocol that is inflexible in incorporating responses to local concerns or suggestions, or indirectly due to a lack of legitimacy to be flexible. When we are talking in reality of some people who have been trained up under rushed circumstances where the key attention is to safety, and these people are often seen as members of communities, but they are often a specific demographic, it may be that additional training/frequent debriefing sessions with frontline staff where local responses and adaptations to protocols (while cornerstone principles are kept intact) can be shared (along with perhaps some excellent case studies where this has already worked well) and such processes of adaptation can be legitimised such that the objectives are both to implement protocols that are both safe and locally relevant. This may be relevant both for burial teams and also people being trained up to man early treatment/isolation units. Knowing when rules can be adjusted or not is tricky, but could be essential in the way people respond to local requests and queries, and ultimately acceptability of the methods elected (Dr Clare Chandler, LSHTM, email communication, 2014).

Examples of behaviour change from other outbreaks

Burial practices should be modified during an epidemic and people are generally open to these modifications, partly because indigenous protocols prescribe to such modifications (Hewlett and Hewlett 2008). The people who wash and prepare the bodies, close friends and family who lie next to the deceased are obviously at risk of Ebola and burial and funeral practices are a primary target of Ebola control efforts by national and international teams. Healthcare workers should build on local protocols and be sensitive to grief and loss by attending funerals, allowing families to view the body, taking a small gift, the family should

decide what to do with the personal effects of the deceased- burn, bury or disinfect them. This supports the long term wellbeing of the family. In Kissi tradition, those dying would usually be transported to an empty house. Custom dictates that one should purify and replace the furniture, clothing, and provisions that are in the room where a death occurred; a custom that could be seen to dovetail with disinfecting houses after a death (Fairhead, 2014).

In previous outbreaks teams have burned all the personal effects of the deceased which alienates family members and friends as it deprives them of familiar means through which to express their grief (Hewlett and Hewlett, p. 78). An alternative suggestion is to place these items in the coffin (instead of, as sometimes, placing them on the grave) with the deceased, or burning items with the family in an important spiritual place. He suggested that a separate Ebola graveyard was not necessary, and family could participate in funerals as long as they wore protective clothing.

Burial teams trained in protective and barrier nursing should bury the deceased, or if this is not possible, provide the family with gloves, bleach and protective gear. It is possible to incorporate protective measures into funeral practices. Some examples are: to help establish trust within the community the international team attended funerals, expressed condolences and shared grief. Also, Alain suggested the burial team communally wash their hands with bleach spray after the funeral, and family and friends join in this ritual. This would make the community aware of the need to use bleach to avoid infection and would symbolically demonstrate solidarity among team members and the community. Also, donating items to support the funeral ceremony is a community practice which can be adhered to (Hewlett and Hewlett 2008).

What not to do

We need to recognise how offensive and dangerous people find the quelling of local funeral practices and disrespectful by-passing of the men's and women's initiation societies and related social institutions that control matters of life, health and death (Leach, 2014). It is the burying community that must decide. Enforcement of little understood sanitation rules by strangers with no connection to the deceased are likely to be resented and resisted. No authority stands above what people consider to be a moral imperative (Fairhead, 2014).

'This is precisely what happened after an Ebola response team faced problems on the death of a pregnant Kissi woman, in what became an exemplary case of cultural sensitivity. The response team ran into opposition from the population concerning the conditions of the burial. The foetus had to be extracted so that mother and baby could be buried separately (as this society believes that the different generations should not be buried together). The response team considered extracting the foetus to be too dangerous. A 'fault' would thus be inevitable – (and being intentional could actually be considered as 'sorcery'). "Without an agreement between the medical teams and the population, the woman could not be buried, and her body began to decompose." Eventually with the intervention of an anthropologist the team realised that it would be possible to repair the fault once it was made. "After discussions with the elders from the young woman's village", they came to an agreement that "there had to be a reparation ritual, consisting of offerings and various ceremonies." The "anthropologists involved asked the WHO to pay for the reparation ritual, and that's how the burial took place' (Fairhead, 2014)

It is important to appreciate how anxious people become when a previously distant state suddenly intervenes –in Guinea the pumping of disinfectant in markets was thought to be pumping virus. There are also unsettled national politics in post-conflict democracies –in Sierra Leone, fears circulated that Ebola was a government plot to depopulate the opposition-supporting east. Distrust of foreigners in the region has been fuelled by decades of extractivism and disrespect, and now by private schemes that accrue great material wealth to some while dispossessing others. In this context fears of sorcery and related body-part theft

circulate as a longstanding idiom, a way of making sense of the extraordinary wealth and power that accrues to a few. The supposed sorcery of today's Ebola outbreak control teams finds a logic in memories and discourses of the slave trade and before – grounded not in traditional myths or timeless culture, but history and political economy, as so well documented by historical anthropologist Rosalind Shaw. One can surmise that such fears may worsen with a heavy-handed militarised response (Leach, 2014)

The Governments of Sierra Leone, Liberia and Guinea have all responded with bans and fines for burying, sheltering or treating suspect patients and corpses. Resistance to response teams and the continuation of traditional burials is undoubtedly helping to continue the epidemic; some burials in particular have become 'super spreading' events. However both media portrayals of the cultural dynamics at work and the Government edicts targeting them are deceptively simple. They belie both the creativity and plurality of regional logics and the institutional context of people's beliefs and behaviours (Wilkinson, 2014, draft report).

'Kissi try very hard to access the last wishes of the dying, as their anger after death would be terrible if it was not heard and respected. How are the last wishes of those dying of Ebola in isolation to be conveyed to their families? Heirs must respect instructions regarding the distribution of property.i Again, how are such wishes communicated from isolation units? It is also correct to give the dying all the food and drink they solicit. Reported incidents of patients being deprived of food and drink in isolation units are not simply 'unfortunate,' but such treatment is highly disrespectful of the dying; disrespect that has terrible consequences for the living' (Fairhead 2014).

3. Not presenting early

Overview of perceptions of Ebola and how this relates to people's actions

One common form of resistance among those suspecting themselves as having Ebola, or having being exposed to it, is hiding, being hidden or fleeing, often across borders. This mode of resistance is catastrophic for the epidemic, preventing treatment, quarantine and surveillance and encouraging spread (Fairhead, 2014). Communities' fears have been dismissed, and framed as arising from their 'ignorance' (<u>http://time.com/3181835/ebola-virus-congo-west-africa/ http://www.npr.org/blogs/parallels/2014/07/10/330390279/in-west-africa-officials-target-ignorance-and-fear-over-ebola ; <u>http://www.rawstory.com/rs/2014/08/ebola-liberians-dying-of-ignorance-say-aid-workers/</u>).</u>

In terms of how people respond to disease, it is firstly important to understand how people understand disease, in order to be able to understand their responses to it and where they go for help (this is also partly covered in the traditional healer section). Fairhead 2014 describes Kissi disease beliefs (an ethnic group living in Guinea, Sierra Leone and Liberia). Whilst there are many frameworks within which diseases are understood and encountered in the region including biomedical and herbal practice, the anthropology of the region is emphatic that disease, however it manifests, is usually regarded as a punishment; a warning. Disease follows from a social fault, but one that the patient must no less confess, or it follows from a curse. Local views, such as in Gabon that ezanga (local name for Ebola) targets people who accumulate wealth and do not share or is the product of spirits, may also be another reason people do not recognise they have the disease, for example one response 'I am a simple man, I share, I am not at risk of ezanga' (Hewlett and Hewlett 2008).

'It is useful to distinguish two rather different types of fault: faults with respect to the natural order and faults in respect to specific ancestors. The first can be spoken of as 'social' faults but it is important to realise that these are not simply social, but they go against 'nature' and as a result have 'natural' consequences simultaneously both for the body **and** for the environment around. One could equally well call them 'natural faults'. For Kissi, a smooth-

running, healthy world is an orderly one in which people, crops, domestic animals and wild animals reproduce as they should, and to this end each of these should reproduce in their correct but separate places and in their correct but separate cycles. People reproduce in villages, crops in fields and animals in the bush. The reproductive cycle for one child needs to be separate from the reproductive cycle of the next. The seeds of one year's crop need to be kept separate from the seeds of the next. Actions that confuse this orderliness in which reproductive cycles of people, animals and crops are mixed, or the reproductive cycle of one year or of one child is mixed with another are the faults that cause ailments simultaneously for people and of the agro-ecosystem. Thus having sex in the bush, not the village demarcated for this, disrupts this order and brings reproductive illnesses on the perpetrators (expressed as a 'tying' of the body) and on the bush (causing drought, crop diseases and a tying' of the bush that prevents, for example, the usual animal movements that enable hunters to make their killing). The blood of menstruation (part of human reproductive cycles) needs to be separated from fields, or both crops and the person concerned will fail to get 'pregnant'. Having sex whilst breast feeding a baby confuses one reproductive cycle with the next, bringing on ailments for both offspring and the mother. Mixing the seeds of one harvest with the next leads to poor harvests and wider fertility problems' (Fairhead 2014).

'What is true of reproduction is also true of death (which for people is the passing into the next stage of life in the 'village of dead'). Death should occur in the village (or sacred forest), not the bush. Deaths in 'the bush' (e.g. such as happen when Ebola patients collapse en route) are faults that can lead to drought, crop diseases and such like. A death in one generation should not be confused with a death in the next, so a mother should not be buried with her fetus inside her (for fear of disrupting not only this world, but also the ancestral one). Those pregnant (in a cycle that is bringing someone into this world) should not care for those who are at death's door (leaving this world). Not everyone can be involved in 'home care' for Ebola' (Fairhead 2014).

An excellent account of the changing narratives of Ebola (*Bolten, Catherine E.."Articulating the Invisible: Ebola Beyond Witchcraft in Sierra Leone."Fieldsights - Hot Spots, Cultural Anthropology Online, October 07, 2014, <u>http://www.culanth.org/fieldsights/596-articulating-the-invisible-ebola-beyond-witchcraft-in-sierra-leone</u>) shows that the narrative about Ebola transformed from something that could be banished with deliberate acts of human sociality into a malevolent force spread through sociality and, among other things, imported technologies and techniques whose power hinged on their invisibility. Rumors emerged that the medical teams were bringing Ebola to remote villages and that Westerners were collaborating with powerful locals to create excuses to snatch the ill for use in cannibalistic rituals. Considering the medical teams who evacuated the sick wore PPE that hid their eyes, covered their skin, and rendered them alien-like, this reaction resonates with the trope of the dangers of the invisible.*

This epidemic has become an epidemic of fear – of 'Ebola panic disease' (EPD) not just Ebola virus disease (EVD) – and 'bending the curve' of transmission below R = 1 – necessary for the epidemic, eventually, to grind to a halt - now requires bending the curve of trust – of agencies and communities in each other - in relation to control efforts (Leach 2014). Due to the symptoms of the disease and the devastating consequences, people would often wish to believe they had other common diseases with similar symptoms, so as not to go to the isolation units and leave their families and also, be exposed to Ebola if they do not currently have it (Leach 2014).

Denial of Ebola has turned to antagonism and provides the backdrop to reports of the disaster: response teams were attacked, villages shut themselves off, and families removed patients from treatment centres and positive cases refused to be admitted to isolation units. Rumours spread that Ebola was an excuse for medical teams to harvest organs or that it was caused by witchcraft. In Kenema, Sierra Leone, a 'running battle' ensued between the police and protestors who were threatening to burn down the hospital and were demanding the

release of all patients. Tear gas was used to disperse the crowds. (<u>http://awoko.org/2014/07/31/sierra-leone-news-insane-mch-aid-nurse-sends-kenema-into-turmoil/</u>, Wilkinson 2014, draft report).

Health-seeking behaviour

'Three recent articles on maternal health all of which emphasise that people have very good reasons to mistrust their threadbare post-war healthcare system. Sierra Leone has the highest official rates of infant and maternal death in the world. Yet, for reasons of trust, comfort, cost, and accessibly most women prefer to give birth with traditional birth attendants (who, in Sierra Leone, are Bundu leaders). I think it's important to emphasise that it is not "superstition" or "ignorance" but rather a lifetime of hard experience which has led people to mistrust formal healthcare' (Jenny Diggins, email communication, 2014) e.g. Herschderfer et al 2012.

When facing illness, many rural Sierra Leoneans display what some might call "fatalism:" ill people and their families often wait in place, consulting healers as much as possible, but not going to hospital, particularly if they judge a person near dead. These life and death choices are made by people living on the margins of subsistence in agrarian settings. One of the villages in Wunde Chiefdom, has some 260 inhabitants and is a few miles from a feeder road and without regular transportation. Of the five other villages within a five-mile radius, two are hamlets that can be reached only on foot, and the very ill have to be transported in and out in hammocks strung on a pole (*Ferme, Mariane.*"Hospital Diaries: Experiences with Public Health in Sierra Leone."Fieldsights - Hot Spots, Cultural Anthropology Online, October 07, 2014, http://www.culanth.org/fieldsights/591-hospital-diaries-experiences-with-public-health-in-sierra-leone).

There are many problems with getting to a care facility, and Ferme (2014) continues using this village as an example of the obstacles. 'There are no state health facilities in this village or in smaller neighboring ones. Five miles away, the former headquarter town, Gboyama, has a two-room dispensary for visits during scheduled hours, staffed by a paramedic who occasionally visits outlying communities. These visits are rare, often months apart. This makes a decision to go to the nearest dispensary—let alone hospitals—a physically challenging one for the ill and those organising their care. Most of the time, rural Sierra Leoneans rely on the expertise of resident herbalists or specialist healers who come to the ill person, instead of requiring him or her to move. Televised images of four-wheel-drive vehicles arriving at the house of an affected victim belie the fact that many rural Sierra Leoneans live in places that are not on motorable roads—one reason health agencies suspect that Sierra Leone may have two to four times the reported EVD cases'.

'For hospital visits, private transportation needs to be arranged not only for the sick but also for accompanying family members who can buy necessary medications and ensure that the patient is fed and that soiled clothes and bed sheets are laundered. Since the 1980s, public hospitals in Sierra Leone have been so ill-equipped that wound dressings, drugs, antiseptics, catheters, and even stitching materials have to be bought by patients. Even purportedly "free" medical care involves expenditures—for supplies, food, and transportation—which most Sierra Leoneans factor into their health care choices. Finally, hospitals are crowded places, where individuals can get lost if they do not have advocates to seek care on their behalf, whereas the healer who comes to their bedside gives them undivided attention' (Ferme, 2014).

For most rural Sierra Leoneans, getting to hospital involves long, uncomfortable, and expensive journeys, navigating Kafka-esque bureaucracies. Repeated payments are required and long waits are interspersed with inconclusive interactions with medical personnel. After all this, one often returns home as one had left or dies from the journey's hardships and lack

of care. What may appear to be inaction informed by fatalism—even avoidance of proffered medical attention—must be understood as a calculated decision about the costs and benefits of expensive care, based on experience (*Ferme, Mariane.*"Hospital Diaries: Experiences with Public Health in Sierra Leone."Fieldsights - Hot Spots, Cultural Anthropology Online, October 07, 2014, <u>http://www.culanth.org/fieldsights/591-hospital-diaries-experiences-with-public-health-in-sierra-leone</u>).

A personal anecdote from the same author, whilst in Sierra Leone shows some of these practical issues with seeking care, and possible reasons for delay, it also illustrates both the resourcefulness of Mende villagers when they want to seek urgent medical care for someone they care about, and the challenges they face in doing so. 'Before the 1991-2002 civil war. I came down with a life-threatening combination of illnesses within the span of a few hours while living in a walk-in village off the transportation grid. Among my symptoms were a very high fever, uncontrollable diarrhoea, and vomit (basically I was incontinent and barely conscious). I probably had cholera, as well as malaria and a couple of other ailments found by later hospital tests. Anyway, villagers made a make-shift toilet from a bucket, fitting a wooden seat for it, so it could be by my bed. Two women washed me and my soiled clothes, and tried to keep me comfortable. After one night with no improvement, the Paramount Chief sent his ceremonial hammock and four young men (a pair of hammock-bearers and their relief) to carry me out, and once we reached a motorable road the man designated to accompany me flagged down a succession of private commercial vehicles to transport me on my journey to Serabu Hospital, which was then considered one of the best outside the country's capital.

He was able to do so because I had given him sufficient cash to pay for transportation for both of us, on each of the three legs of the rest of our journey. By the time I arrived to the Serabu emergency ward I had spent about fourteen hours on the road—some in various states of unconsciousness, all in great discomfort in packed, hot vehicles travelling bumpy dirt roads—and had paid more than my neighbour's annual cash reserves in transportation alone, for myself and my companion. When I discharged myself from the hospital a week later to convalesce at a friend's home, my bill added up to some \$250 (US), which was about three times my friend's monthly salary—that of a Freetown-based, trained nurse-midwife employed in a government hospital. She supported a household of 4 adults and 5 children including 3 who required fees, uniforms, and daily lunch and transportation money to attend school-- on this income, and on occasional business ventures marketing oil and produce sent to the city from her rural-based relatives.

I tell this story for 3 reasons: 1) to show how resourceful and inventive people can be when confronted with disease (making me a toilet, finding a way to get me out of there and to a hospital)--they are not trapped in timeless cultural practices, they think quickly on their feet. 2) how expensive it is to take the hospital route--they took it with me because they knew I had the money to pay for it, and that I would expect to be taken there. 3) that the expectation (as I pointed Anthropology link: out in my Cultural online piece at this http://www.culanth.org/fieldsights/585-ebola-in-perspective) is that you never send anyone alone to hospital: you need someone to accompany, advocate, purchase supplies, food, etc. for you, and report back to the community on the outcome of your visit, for reasons outlined in that piece' (Mariane Ferme, email communication, 2014).

Information from other outbreaks/countries

Hewlett and Hewlett describe their experiences in Gabon in the chapter 'Outbreak Ethnography' and how local people were reluctant to talk about what had been happening and admit that people had died from Ebola. Villagers, priests and local government officials supported the denial even though laboratory tests indicated Ebola. Distrust of the international team was not surprising given local people's experiences with the French and American teams during an Ebola outbreak in 1996. People described that international teams

came and took blood but never returned to give the results, and many children died after their blood was taken. People thought the blood was repeatedly harvested by Euro-Americans for sale in Switzerland (Hewlett and Hewlett 2008).

There are many instances of people not presenting for care early and also of people hiding from humanitarian teams who they feared would spread the virus to them. (Faye 2014). One examples of an incident in April is: A well-respected, forty year old woman from the village had been a close contact of a positive case hospitalised in an Ebola Unit in Gueckedou and while she was under surveillance, she 'escaped' from the village to Vengbemei village, Foya district, in Lofa County. Yet surveillance teams found that she had symptoms before her escape, being "afraid to come to the Ebola unit in Gueckedou". They tracked her down in Liberia and returned her, where she died in the Gueckedou Centre. Distrust caused several Ebola-hit villages to cut themselves off: "We don't want any visitors.... We don't want any contact with anyone," referring to Doctors Without Borders. "Wherever those people have passed, the communities have been hit by illness." (http://reliefweb.int/report/liberia/ebola-virus-disease-epidemic-liberia-situation-report-sitrep-no-26-0900-hrs-6th-june, http://www.scidev.net/global/cooperation/feature/anthropologists-medics-ebola-guinea.html, http://www.nytimes.com/2014/07/28/world/africa/ebola-epidemic-west-africa-guinea.html? r=0)

Note that methods of cutting communities off and of isolating infectious patients date back in the region to the era of Smallpox. "Preventive measures are sometimes taken by an entire village against such calamities as smallpox. The epidemic nature of smallpox is well known to the Kpelle people, and a town in which a case has been found is quarantined by native custom as well as by national law. Smallpox patients are usually isolated on a little-used path in the forest; however, this is an emergency measure against real disaster", "There is a sort of isolation..... It is used in cases of serious skin diseases such as phagedenic ulcers. The victim is isolated in a house in town; the house is fenced; and only one person (often the wife of a male patient) may approach the house to bring food. A person who has been treated in this way may thereafter be known by the nickname ze'nsi 'the isolation', and shows no offense when the name is used." (Welmer 1949)

Behavior change: How can isolation units be modified so they are culturally sensitive and appropriate?

There are also beneficial practices in the local culture and context: local populations have the knowledge, cultural logic and practices that arguably can and should be integrated into responses (Leach, <u>http://www.who.int/bulletin/volumes/88/7/10-030710/en/</u>). Using large tarp barriers to enclose isolation units prohibit family access to their sick and dying relatives, picket fences make the work of the isolation unit more transparent, other things that can help is allowing people to have some personal items and allowing family members to view the body as it was being placed in a body bag (Hewlett and Hewlett 2008).

What not to do

In Sierra Leone, people live communally, caring for family and social networks through the sharing of food, work, and the fostering of children. Witches, as antisocial consumers, are the antithesis of human beings. A witch's power derives from the consumption of human flesh and human potential, implicating them in ritual killing and cannibalism. Unlike humans, witches in their human forms live alone and eat alone, and, most disturbingly, grow wealthy through unseen means. Their wealth is linked to a parallel invisible world that they inhabit at night, a "witch city" that is technologically advanced and dominated by many of the material items—such as cell phones—that are now implicated in the spread of an equally deadly, also invisible force. As Ebola education campaigns intensify, their message—no hugging, no handshakes, no caring for the ill, and no handling of the dead—creates clear linkages to the

malevolent world of witchcraft. Ebola is a disease that destroys people's ability to be human (Bolten, Catherine E.."Articulating the Invisible: Ebola Beyond Witchcraft in Sierra Leone."*Fieldsights - Hot Spots, Cultural Anthropology Online, October 07, 2014,* <u>http://www.culanth.org/fieldsights/596-articulating-the-invisible-ebola-beyond-witchcraft-insierra-leone</u>).

In the last two weeks, an even more disturbing set of rumors has emerged from the Northern Province. In several towns where the WHO reported an upswing in Ebola deaths, text messages circulated that these deaths were not due to a virus but to the fact that multiple witch airplanes crashed into densely populated neighborhoods. All the witches onboard were killed, as well as some unlucky souls on the ground. According to my contact in the north, "This gives new meaning to the phrase 'airborne transmission!" She noted the resonance with a rising belief in the region that the illness spreads through airborne malevolent intent, from witch planes to witch guns, by which evildoers invisibly shoot their targets and cause imminent death. Interpreting Ebola in these terms means that the witches are now handling something that is so dangerous, so foul, it escapes their own ability to control and manipulate. Considering the number of health care professionals, including many foreigners, who have become infected and died from Ebola virus disease, these rumors illustrate witchcraft as potent commentary on the inability of the most powerful people to manage the forces of suffering and death. A witch plane crash is evil out of control, and so is Ebola (Bolten, Catherine E.."Articulating the Invisible: Ebola Beyond Witchcraft in Sierra Leone." Fieldsights - Hot Spots, Cultural Anthropology Online, October 07, 2014, http://www.culanth.org/fieldsights/596-articulating-the-invisible-ebola-beyond-witchcraft-insierra-leone).

Secret knowledge, and membership of particular societies which offer access to that knowledge (to different degrees) characterizes this region of West Africa. Much about the medical response may resonate with these themes: hiding patients behind screens (in isolation), wearing masks (protective clothing). It may be that medical teams are interpreted as another 'secret society'. Response teams should be sensitive to these possibilities and aware of their why they may face resistance (Wilkinson, 2014, STEPS blog).

4. Care at home

Local beliefs

There is distrust of international healthcare workers and local people may be suspicious of their activities (Hewlett and Hewlett 2008). Some fears from DR Congo, Congo, Gabon, Uganda and Sudan are that isolation units extract and sell body parts (Hewlett and Hewlett 2008). Colonial history and global-political-economic structures contribute to inequality and suspicion, and add to the accusations that healthcare workers have started or amplified outbreaks and people asking them to leave (Gabon) or hide from them and being reluctant to seek treatment (Uganda, Congo, DR Congo, Sudan) or disbelieve that there is an epidemic (Congo, DR Congo and Gabon). All these are health lowering issues.

Gender roles are also an important aspect of care at home. Women are the primary caregivers of the sick (McCormack 1985). However, the exact social relationship between the carer and the terminally ill depends on the social structure. In coastal Sierra Leone young women move to their husband's village on marriage, but return to their home village when very ill. Please see the figure below.

Who gives care to:		
Patient	Male patient	Female patient
Infant	Mother	Mother
Child	Mother	Mother
Young married adult	Wife. Perhaps mother	Mother. Perhaps mother-in-law
	Wife	Daughter. Perhaps sister or daughter-in-law

Source: MacCormack 1985

'In the Ebola outbreak, home care is going to be very complicated - in the absence not just of water but buckets too - so it seems vital that local institutions could be used to mobilise support systems to help households when they find themselves in the position of caring for the sick. To ensure that even, if the carer in the 1+1 model was the only person who had contact with the patient, they at least had practical (and emotional) support' (Annie Wilkinson, email communication, 2014).

In some cultures, preparing and washing the dead for burial is especially important once an epidemic has taken hold (as previously hunters may have been at more risk), as there are more sick to care for. In the Uganda outbreak women experienced substantially greater mortality than men (Hewlett and Hewlett 2008), but health education messages did not target them.

Behaviour change

Healthcare workers should make activities as transparent as possible and develop trust and rapport with local people, for example the previous example about using picket fences instead of tarp for isolation units. Regular community meetings to explain control efforts and the importance of isolation units, attending funerals, walking in the community and acknowledging local people all help. Most people want and value outside help, as long as feelings of mistrust are not amplified.

In terms of risk to caregivers, health education and social mobilisation efforts and meetings should target women and women's groups and teams would be aware of their roles in caring for the sick and performing burial practices. Social mobilisation is a key component because all stakeholders should be involved to enable pooling resources and optimizing management of epidemics (Chippaux 2014).

With the potential move to home-based care — it is worth considering how to collaborate with 'secret' societies as these sodalities in order to disseminate public health messages. To outsiders (probably including the British army, WHO, IRC, MSF etc.) 'secret' societies appear inscrutably exotic and intractably 'traditional'. However, they are also one of the most robust, well-trusted institutions in rural areas' (Jenny Diggins, email communication, 2014).

'Historically, the Poro and Bundu were the most powerful political institutions in the region. Their power has been eroded by the introduction of Western forms of education and governance, but they continue to fill a whole range of very practical roles: especially in more remote parts of the country, were 'the state' has had minimal effective presence since before the war. So, for example, in Kagboro Chiefdom (where Jenny lived): it is the Poro society that mobilises men to mend potholes in the road, or clear the land around the town's health clinic from the encroaching forest. It is no coincidence that, during the war, when the state army failed to protect local communities, village residents drew directly on the model of the initiation society to organise young farmers into an effective civil defence force. Societies are an institutional structure that people understand, and trust, and that communities fall back on in times of crisis.

So, if there is going to be an urgent effort to provide men and women with the knowledge and resources to safely care for sick relatives at home, then it may be that the Bundu and Poro societies would be one of the most effective routes for disseminating vital knowledge, and building the structures needed for home care. In the town I lived in, Bundu leaders could summon hundreds of women to their society bush at a moment's notice' (Jenny Diggins, email communication, 2014). Bundu leaders are already respected within their communities as health experts and, in some parts of Sierra Leone, there is a precedent for Bundu leaders receiving midwifery training from medical doctors, and using the Bundu bush as a space in which to pass that knowledge on to other women (Jambai and MacCormack 1996).

'Attention also has to be paid to how to make Ebola cases less hazardous for others, either during the process of transfer to a treatment facility or in extreme sickness and death. Single room/single carer models have been proposed. Feedback is needed from villages about the way the single carer would then be treated. One issue will be the expression of empathy for the bereaved carer, after a death has occurred, since body contact with the carer might be hazardous. There is a rich local culture of gift giving in rural Sierra Leone, and villagers should be engaged in discussion about how this cultural idiom might best be adapted to take account of EVD' (Fairhead, 2014).

'As MacCormack suggested: "If seriously ill people do enter hospital, staff must allow 'chaplaincy' visits from lineage and secret society elders, who are highly respected members of the community." Impending death is a time for ensuring that all is well in relationships between the living and those about to make their final transition. Peace must be made "lest they become wrathful ancestors... Hospitals must allow for visits of extended kin, and for ceremonies of reconciliation to be carried out on hospital premises. Otherwise the elderly patient may be taken away from hospital before a course of treatment is completed." Such 'escapes' of Ebola patients from hospitals with the support of their kin, have been a well reported feature of resistance within Ebola treatment centres. Long before global concern with Ebola arose, MacCormack recommended that in planning all health provision in this region "that lineage and secret society chiefs must participate in the planning and implementing of primary health care initiatives. They have been the health educators, herbalists and midwives for millennia, and their concern for the health and fertility of their people in genuine."" (Fairhead, 2014).

5. Visiting traditional healers

Local beliefs leading to visiting traditional healers

Firstly, it is important to consider how disease is viewed within African culture. Disease is usually regarded as a punishment; a warning and sorcery is often used to explain rapid deaths in early stages of an outbreak (Hewlett and Hewlett 2008). Disease follows from a social fault (even if an unintentional one) and sorcery/disease is often linked to accumulation of wealth, lack of sharing and cooperation and explains a variety of misfortunes. In Kissi (an ethnic group in Guinea, Liberia and Sierra Leone) tradition when an infection becomes serious after simple remedies have been tried, a patient or their family will usually approach a diviner (*wanayawa*) who consults an oracle. The answer hardly varies. The patient has committed a fault which they should confess/reveal or their condition will worsen. "If you want to get better, you must reveal the improper action you have committed. If you do not speak, it is death. If someone has done good, done a service and in return you have slandered the benefactor, it is death. Forget nothing in your confession and you are saved; if

you do not confess everything, you inevitably die." (Fairhead 2014). In Gabon, local healers called ngangas diagnose and treat ezanga (local name for Ebola). They use their visionary forces to see it and use a variety of techniques to extract ezanga. Not all healers treat this disease as the disease can be stronger than the healer and cause the healer's death (Hewlett and Hewlett 2008).

Those involved in the control effort have offered similar views. As one Sierra Leonean doctor commented "The people living in these areas said there's no such thing as Ebola". The same doctor continued "They have their traditional beliefs and their traditional cures and they look up to their traditional leaders. Until we can bring the traditional leaders onside, it will be very difficult to convince them that Ebola even exists'

(<u>http://www.theguardian.com/world/2014/jul/02/-sp-ebola-out-of-control-west-africa</u>) In Sierra Leone the fact that an early cluster of cases involved a traditional healer was used as evidence to support such explanations1 (Wilkinson 2014, draft report).

Secondly, there are different kinds of informal health workers. It is not helpful to think of this as traditional and biomedical but perhaps more as locally embedded and/or renowned, or less so, along a spectrum. Part of being embedded in localities and regional networks, will be being embedded in local institutions such as the societies, as in the case of TBAs. But it could also mean village (or urban section) politics, economies, marriage etc. Their legitimacy then comes from demonstrating skill and compassion to the community, in the context of what is appropriate for these institutional ties (Wilkinson 2014, draft report and http://tenplay.com.au/news/national/latest-news/features/365-ebola-deaths-traced-back-to-healer).

Reports have emphasised the problematic role of traditional beliefs and practices assumed to be unchanging and favoured by local populations. A blog in the Economist described Ebola's spread in these terms "Many people in Sierra Leone, where an Ebola epidemic has gripped the country for the first time, refuse to accept that the disease can be tackled by Western medicine. They prefer to use traditional healers instead. This may make it spread faster.....The Sierra Leonean authorities are therefore up against both a health-care problem and a cultural one. Traditional healers and herbalists are popular across West Africa. With secret recipes of herbs and potions, they claim to cure everything from the common cold to malaria."

⁶During the first outbreak, described by Peter Piot in various places, they had to rely heavily on local traditions of handling the ill, including isolation with a single caregiver if I recall correctly. There also is the reverse cultural anthropology of nosocomial and healthcare associated illnesses that involve ebols ("study back"). Sometimes there is a form of fetishized scientism that, like the nuns reusing needles in 1976 can be lethal; especially when these fetishized practices are not critically evaluated for whether they are appropriate and work; or have the conditions to work' (Daniel Cohen, email communication, 2014).

A village studied by Annie Wilkinson in her PhD research 'had TBAs, an Imam, plus healers at various points on the "traditional" and "biomedical" scale (categories we know aren't mutually exclusive). For example, there was a man who had worked as an assistant in a pharmacy in a larger town who had married into the village and was now the de facto village doctor, providing biomedical treatments. He accepted deferred payment or rice (and sometimes nothing), and tied by kinship, he seemed genuinely to work hard for the community. He was greatly respected and appreciated and was building up a network of patients in surrounding villages too. In contrast another man would turn up once a month with a suitcase selling both herbs and pharmaceuticals. People were more disparaging about him though they also bought his produce, presumably out of lack of other options. This was a much more financial transaction. Attitudes to him were similar to attitudes about the government facilities which were also seen as primarily a financial interaction.

Urban settings, I think, also work on networks of authority and personal relationships for both the formal (government and private) and informal sectors, and sometimes between them. Certain practitioners definitely have renown and people will travel far to see consult them especially (Annie Wilkinson, email communication, 2014).

How this affects health seeking behaviour

If people believe that sorcery causes the illness they will not limit the victim's personal contact with others, they will be less likely to seek biomedical treatment at a clinic or hospital. This is because sorcery illnesses are not transmitted by touch and must be cured spiritually, usually by a healer who extracts the poison darts or identifies who sent it (Hewlett and Hewlett 2008). In Congo a person can go to a church and ask God to extract the sorcery. In both Congo and Gabon, local people treated symptoms of sorcery with medicine and antibiotics (Hewlett and Hewlett 2008, p117).

'There are cultural attitudes ("western") that affect decision-making around health-seeking behaviour. I mentioned to others that Chippaux is too polite about sex, not using the word "semen". Although it would be nice if the very few observations of viral persistence in semen (40 days after recovery, CDC recommending 90 days abstinence) had been repeated by others, which really would not be that hard to do, and breast-milk as well. No one, to my knowledge has mentioned anal sex, or oral sex with mouth sores or other practices that have higher likelihood of infection for Ebola (as found for AIDS). Maybe even post discharge. Politeness can kill. We could at least increase our anecdotal knowledge by monitoring the western survivors' (Daniel Cohen, email communication, 2014).

'However, even the most remote rural populations should not be assumed to be unfamiliar with concepts of modern medicine, however their engagement with them may be mediated by other logics. People are accepting of Western medicine but are ambivalent about the formal health system. The history of Lassa fever, another viral haemorrhagic disease which has been recognised as endemic in the area for decades, is relevant. For example, there are longstanding rumours about medical staff administering lethal injections. Patients have been known to avoid the Lassa ward in Kenema.

Underlying health seeking patterns, is the fact that people hold multiple models for interpreting and responding to sickness. In <u>Mende</u> areas, there are general categories of big and small fever, and ordinary and hospital sick, as well as specific biomedical diseases. Lassa was classified a 'big fever' and Ebola may well be too. Diseases can be understood as caused by multiple things, including germ theory or 'witchcraft'. These causes are not necessarily mutually exclusive. A diagnostic test which 'proves' someone has an illness may not be viewed as conclusive. Key to understanding health seeking is to understand how disease categories shift as the illness progresses. The way people and those around them have behaved, the events leading up to the illness and circumstances surrounding its onset all influence the model which is applied and the treatment sought' (Wilkinson, 2014, http://steps-centre.org/2014/blog/ebola/).

What modifications can be made to change behaviour?

All healthcare workers should be aware of and expect a sorcery explanation for Ebola, especially at the beginning of an outbreak. Respect and understanding for the socialeconomic-spiritual context can develop rapport and build trust. Also, people are often open to biomedical treatment even though they believe sorcery is the cause. Being able to use local criteria to distinguish sorcery from epidemic illness is useful.

What is the potential for mobilising/supporting informal health workers in providing more/better care for patients with suspected/confirmed Ebola and for other conditions?

'It is traditional healers' capital, networks and institutional ties which hold potential if mobilised/trained/sensitised/linked in to the response. They might be useful in referral, surveillance and prevention communication. Also for providing care, which of course they are already doing, but if and when the government officially move to home and community care then I think these health workers could be invaluable for supporting, staffing and lending legitimacy to those (if they want to, which is another issue!). Might also need to think about unintended consequences here – destroying the few trusted care networks there are if things go very wrong.

However, for all my talk of legitimacy, perhaps Ebola is being perceived in such a way that these providers are not seen as legitimate care providers? I'm unsure about this, but we do know that the hospitals are not seen as legitimate either. There is also, in Mende areas at least, diseases which are understood as 'ordinary sicks' and ones which are 'hospital sicks'. But there are also ones which are definitely NOT hospital sicks, which are caused by other things (faults, transgressions, bad intent) and where care is sought out of the hospital system. In these cases biomedicine can't help and may make it worse. I suspect in some cases Ebola is fitting into this last category (not helped by the health messaging which said so clearly at the beginning that there was no treatment for Ebola) (Annie Wilkinson, email communication, 2014).

What are the broader considerations that should be borne in mind should an external organisation wish to do so?

'Basically as above, they are not all the same, some are trusted and others are not. Some are well networked and others are not. They might not all want to help, and they may not all have communities best interests at heart. There may be friction between different providers and institutions. Finding out about well known providers in particular localities would be a good start – also asking them who they work with (perhaps they refer to a particular doctors or pharmacist – or one of the private laboratories). Also about any associations they may be part of which could be another network to tap into, e.g. if pharmacists have professional associations? Even the informal ones'. (Annie Wilkinson, email communication, 2014).

Would the approach be different for informal health workers who broadly offer biomedical treatment modalities, and those who broadly offer non-biomedical treatments?

I don't think it is necessarily hugely different. The main thing would be to engage in a respectful way as we have been advising elsewhere. More important might be how you do it in a village setting and an urban setting. Saying this, for some providers and the institutions they are embedded within, there may be particular sensitivities i.e. for TBAs there will be sensitivities about gender and secret knowledge, but this does not mean they are impenetrable. (Annie Wilkinson, email communication, 2014).

What not to do

Crucially, Ebola is transmitting through neglected health systems - a legacy of conflict and underdevelopment, of aid and development intervention fragmented under multiple NGOs and private sector agencies and beset by corruption, failing to build basic capacity. Sierra Leone's population of 6 million is served by about 120 doctors and as resource-poor hospitals

became infection grounds, many succumbed. They included Dr. Khan at Kenema Government Hospital, the country's only haemorrhagic fever specialist. More than 10% of deaths have been of healthcare workers that these countries couldn't afford to lose. The recent aid focus on universal access hasn't been directed in ways that would build the resilient accessible networks of rural health and paramedicine that might have led rural people, in pre-epidemic contexts as well as now, to see hospitals and health centres as places of care – as opposed to ones to be avoided, neglected, in favour of home care and traditional healers within their pluralistic framings of disease and therapy (Leach, 2014).

What local people are doing

Currently, it is the deep rural areas that have managed to isolate themselves from such 'development' that are now successfully isolating themselves from Ebola, drawing on stillintact chieftaincy and local structures to enact bye-laws to prevent kin from infected areas entering. Malema Chiefdom, where I lived in the late 1980s, is surviving Ebola as it survived the war – and very likely the smallpox epidemics of the 1970s – by withdrawing, and locallymanaged quarantines (Leach, 2014).

6. Decision making around health seeking behaviour

Care seeking behaviour and Ebola in Sierra Leone (Lipton 2014)

[']During times of illness people often stay with close family who care for them. Sometimes this involves medium and long distance travel, such as when those living upcountry come to the city for better access to medication and healthcare, or city dwellers travel across town to family compounds. Routine illnesses, such as Malaria, have similar symptoms as Ebola, so they do not necessarily cause as much alarm as might be expected.

When people get sick they often inform their friends, family and neighbours, who show sympathy, provide financial support, medicine, food, and prayer. People are now wary about publicizing their illness as they might be considered to have Ebola, and reported to the authorities. This also intensifies the desire to be with close family who can provide protection. Those who are more socially distant, or have strained relations, are more likely to report someone to the authorities than close family.

Although medical doctors are generally highly respected, and people in Freetown are normally keen to seek medical attention (at pharmacies and hospitals) if resources permit (people often borrow money from friends/family), 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.

Many continue to buy medication from local pharmacies, but are forced to in underhand ways now that they many are officially banned from operating.

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 (traditional healers)'.

7. Behaviour during a health crisis (cholera crisis)

It is important to consider that people's behaviour changes during epidemics, something that is often left out of traditional disease models which ignore social science and anthropological approaches. Leach and Scoones (2013) provide a valuable critique of outbreak models: The resulting slow viral spread presented was central to the projected success of the model control strategy, requiring local containment within 30 days. Yet, other work suggests that outbreaks are especially common in peri-urban semi-intensive poultry production areas, where the disease may spread much faster. Spread was modelled from a 1994 migration and work survey, but this was restricted to formal workplaces, ignoring movement associated with informal activities. The model assumed no changes in behaviour as the pandemic accelerated, ignoring possible absences from schools, workplaces and other social distancing. Finally, it was assumed that implemented measures for detection and movement restriction would work smoothly e heroic assumptions contradicted by other studies (Safman, 2010; Scoones, 2010).

Padmawati and Nichter (2008) carried out ethnographies of formal and informal commodity chains, from production through distribution to marketing. They found that likely exposure was highly differentiated by age, gender and occupation, while risk perceptions significantly affected people's behaviour, with clear implications for any age or sex-structured model.

An online article explains how during this health crisis there have been narratives emerging which draw parallels to the war. Ebola invaded Sierra Leone using an eerily similar path as Revolutionary United Front rebels twenty-three years ago. From Kailahun, the farthest eastern district, the virus has coursed its way, inch by destructive inch, into the heart of the country and the imaginations of Sierra Leoneans. Along the way, it has met with varying public attitudes and a government response that parallels what the rebels encountered as they marauded through the countryside to eventually lay waste twice to the capital Freetown. It is in the competing narratives of the outbreak that the comparisons have been most striking, however, as two publics have emerged—each adhering to a version of events to reinvent others in a time of Ebola. This essay narrates these efforts and reflects upon the implications for political stability in the Mano River region (*Batty, Fodei."Reinventing "Others" in a Time of Ebola . "Fieldsights - Hot Spots, Cultural Anthropology Online, October 07, 2014, http://www.culanth.org/fieldsights/589-reinventing-others-in-a-time-of-ebola)*

8. Effective behaviour change interventions- what is acceptable/appropriate

Bending the epidemic and trust curve needs community collaboration, local involvement, respectful dialogue and joint solution-finding, in areas like ritual creativity to identify new burial practices that meet both socio-cultural needs and infection-reducing protocols; and in how triage and treatment units are located, designed and staffed. Fortunately those designing and funding the response are now listening. But will it be quick enough, and can it overcome such a history of de-development and structural violence? (Leach, 2014)

It is important to have 'a clear sense of the institutional fabric of rural areas. A lot of the discourse around this health crisis has been one of "state failure". At a local level (in rural areas, at least) there are some fairly robust, well-trusted, institutions. Sadly, I think this is less true of urban areas. There is a potential role of the Bundu and Poro Societies in the Ebola response. One of the most distinctive characteristics of social life for most language groups across this region, is the central role played by gendered initiation sodalities. Across rural regions, almost every young women is initiated into the Bundu society, whilst every young man is joined into the Poro. Initiation involves a period of seclusion during which initiates undergo a series of ritual and bodily transformations, and are taught esoteric and practical knowledge necessary for adulthood.

To outsiders (probably including the British army, WHO, IRC, MSF etc.) these so-called 'secret' societies appear inscrutably exotic and intractably 'traditional'. However, they are also one of the most robust, well-trusted institutions in rural areas. I think that — with the

potential move to home-based care — it is worth considering how to collaborate with these sodalities in order to disseminate public health messages.

Historically, the Poro and Bundu were the most powerful political institutions in the region. Their power has been eroded by the introduction of Western forms of education and governance, but they continue to fill a whole range of very practical roles: especially in remoter parts of the country, were 'the state' has had minimal effective presence since before the war. So, for example, in Kagboro Chiefdom where I lived: it is the Poro society that mobilises men to mend potholes in the road, or clear the land around town's health clinic from the encroaching forest.

It is no coincidence that, during the war, when the state army failed to protect local communities, village residents drew directly on the model of the initiation society to organise young farmers into an effective civil defence force. It strikes me that societies are an institutional structure that people understand, and trust, and that communities fall back on in times of crisis.

So, if there is going to be an urgent effort to provide men and women with the knowledge and resources to safely care for sick relatives at home, then it may be that the Bundu and Poro societies would be one of the most effective routes for disseminating vital knowledge, and building the structures needed for home care. In the town I lived in, Bundu leaders could summon hundreds of women to their society bush at a moment's notice. Bundu leaders are already respected within their communities as health experts and, in some parts of Sierra Leone, there is a precedent for Bundu leaders receiving midwifery training from medical doctors, and using the Bundu bush as a space in which to pass that knowledge on to other women (Jambai and MacCormack 1996)' (Jenny Diggins, email communication, 2014).

Community engagement brief (draft)

Reflecting comments from Paul Richards, Melissa Leach, Ann Kelly, Almudena Mari Saez, Pauline Oosterhoff and Annie Wilkinson

'Entry into a rural community using a staggered approach seems sensible, as does a participatory approach which builds on the knowledge and perspectives of the community, this may not work so well in urban areas. A good feature is the emphasis on addressing other community needs, not just Ebola. Having a clear focus on the collateral damage done by Ebola is a community concern, and thus a very good opportunity for a meeting of minds. Also, be mindful of difference within communities, men, women, children, more and less powerful communities members are all different.

Meetings are usually held in buildings known as a court or community barri. A barri meeting is the place to hold discussions with elders, and others may be allowed or encouraged to attend. There are protocols for such meetings (the visitors need to know the gift protocols, for example).

Facilitating a community meeting is a skilled process. Some key points from the experience of our team, especially colleagues at Njala, are:

- The meetings will have to be held in local languages, with translation not for the meeting but for the visitors.
- The work of facilitating the meetings has to be done if possible -by trained local teams.
- As the community is not a harmonious entity it is a good idea to hold separate meetings for men, women, elders, youth, and children, followed by plenary sessions which might bring delegates of these groups back together. Our team have found talking to the children - girls and boys separately was extremely illuminating.

 A feature of these meetings was having a facilitator and a separate person to monitor side talk. A village barri is open-sided and there is constant commentary coming from those who are half in the meeting, or outside and listening from a distance. A common experience is that there will be agreement from the main part of the meeting, that turns into disagreement when the additional commentary is taken into account

Assume knowledge not ignorance, start discussions by establishing what people know, understand or think; build from there to offer and share information on what is known, including correcting any misunderstandings arising from prior misinformation (for example about Ebola and bushmeat, or that there is no treatment, or that Ebola always kills. Meeting with key groups separately, taking active steps to record dissent, plenary sessions to probe the dissent. Not rushing and possibly repeating the whole process to give dissenters ample time to express worries and be encouraged that the process is taking their views into account. The aim would be to build up a clear, shared understanding of a set of key points around the relevant issue (for example what one needs to do to minimise infection risks; the transmission pathways of Ebola and hence how to minimise risks, and to discuss openly what to do - with the aim of generating jointly-produced, and therefore owned, solutions which are grounded in local realities and therefore more likely to work

- If possible, having trained local people (by which we mean very local not just from Sierra Leone) is important for languages, to navigate nuances and variations in local protocol such as those around gifts, and also to ensure that exactly the right people are respected and included in the right ways (for example, not just categories, but which particular elders, society officials etc. – also local healers, pharmacists....
- Finally, when asking people to identify what are the most important health issues in their locality be careful about the expectations you might generate. It will perhaps help to offer practical and achievable deliverables: wash and sanitation in the village, at school, (latrines, cleaning wells, repair water pumps, etc.), clotheslines and health centres for whole population. This will be necessary anyway to set the ECU and will be a benefit for the whole community and not only for Ebola patients. And it may help the community to trust the outside team'

Systematic underdevelopment (Scoones, 2014, <u>http://www.huffingtonpost.co.uk/ian-</u>scoones/ebola-international-development_b_5975608.html).

'On a wider scale, the Ebola crisis has exposed the consequences of a pattern of systematic 'underdevelopment' or 'structural violence', and the implications of deep-seated unequal global relations. Yet poverty, inequality, conflict and unsustainability in poor, far-off places can usually be ignored. Pigeon-holed into suitable labels of 'conflict prone', 'failed state' or 'weak governance', development acts to displace such challenges. Yet viruses know no boundaries, and the threat of the Ebola outbreak has rung alarm bells far away in the seats of global economic and political power (Scoones, 2014, <u>http://www.huffingtonpost.co.uk/ian-scoones/ebola-international-development b 5975608.html</u>).

Unsettling questions are raised. We must ask whether the Ebola crisis is in large part the result of failed development, and indeed systematic underdevelopment and inequality entrenched by development policies imposed by western countries. For many years, West Africa has suffered the consequences of structural adjustment and economic reform pushed as a condition of aid. This has resulted in the hollowing out of states and the decimation of public services, including health systems. In poor countries in West Africa, this active neglect has surely been a contributory factor to the devastation being wreaked by Ebola. This in turn has been compounded by shifting service provision to the private sector and failing to train

professionals and support state capacity in health and other services. This has resulted in an inability to spot and respond to the crisis, both in West Africa, but also internationally.

Zoonotic diseases such as Ebola initially emerge due to a complex combination of ecological, economic and social drivers. We don't know the details of the recent Ebola emergence, but we must ask whether development policies have been part of the cause. For example, does an advocacy for private sector investment - in mining, large-scale agriculture and so on - result in forms of ecological and social dislocation and disruption that feed into such crises, facilitating spill-over and spread of disease? Complex ecological dynamics in forest-farm ecosystems may have resulted in changes of bat-human interactions causing the disease to spread. But again, we must ask whether environmental and land use policies have at least been in part a cause. For example, have our poor understandings of environmental and forest change, and the top-down interventions that have been promulgated by donors, NGOs and governments made things worse?

The most affected countries in West Africa have been subject to long-running conflicts. These have resulted in population movements, changes in social dynamics and deepening poverty. Development aid efforts have invested considerable sums in post-conflict 'reconstruction'. But we must ask if much of this has missed the mark, failing to build social relations, community fabrics and institutions that provide the basis for effective responses to disease outbreaks, and the forms of resilience needed to weather crises. Reconstruction may have been only superficial, creating new forms of vulnerability to unexpected shocks such as Ebola.

Where growth has happened following conflict, it has been exceptionally uneven. Inequalities and vulnerabilities have risen. We must ask whether rapid urbanisation, precipitated by unequally distributed economic growth, has created new forms of vulnerability, especially for the poor. In the absence of urban planning and effective service provision due to inadequate state finances, the conditions for rapid spread of disease is set, exposing the most marginal to heightened risks'.

In terms of lessons for development, these stories tell us that humanitarianism is vital but it must be early enough, and appropriate. It tells us that development as aid to so-called 'fragile states' is important, but that if privatised, fragmented and spent in projects not attuned to local realities and knowledge, it can be deeply unproductive and damaging – as so much around health, environment and rural development in the region has been (Leach, 2014).

9. Summary of the Ebola Response Anthropology Platform

The Ebola Response Anthropology Platform is co-ordinated by anthropologists at LSHTM, IDS and the Universities of Sussex and Exeter, this aims to contribute to a co-ordinated, adaptive and iterative response to the Ebola outbreak. By drawing upon existing anthropological expertise, and undertaking targeted fieldwork, the aim is to enhance current efforts to contain the epidemic by providing clear, practical, real-time advice about how to engage with crucial socio-cultural and political dimensions of the outbreak and build locally-appropriate interventions.

The specific objectives of the Platform are:

- 1. To identify, connect up and support in-country anthropological and other social science capacity working in African countries affected by Ebola and to provide a basis for interaction with clinical, scientific and outbreak control teams.
- 2. To help key stakeholders, practitioners and researchers to access information, findings and background resources about the socio-cultural, historical, economic and political dimensions of Ebola.

- 3. To support relief teams and in-country clinical and social scientific capacity through training and guidelines oriented towards strengthening community-based activities
- 4. To provide rapid responses by e-mail, conference calls and web-based dialogues to operational questions raised by those working for NGOs, government and international agencies about how to contain the epidemic effectively.
- To cultivate appropriate anthropological resources and networks positioned to mobilise a rapid, substantive, socially-informed response to future Ebola outbreaks in vulnerable places - – such as Mali, Cote d'Ivoire, Senegal, Uganda, South Sudan, DRC
- 6. To inform global health policy by drawing lessons from the Ebola response and advancing a comparative perspective on Ebola and other emerging infections, around key themes such as: the interface between justice, security and emerging infections; ethics, pharmaceutical trials and humanitarianism.

The Platform is just getting up and running but the page has had 313 views in less than 2 weeks. Fred Martineau and Melissa Parker, LSHTM are key contacts for the platform. The temporary website address is: <u>http://www.heart-resources.org/ebola-response-anthropology-platform/</u>.

7. Additional information

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