

Social science lessons learned from Ebola epidemics

In this 'Social Science in Epidemics' series, different aspects of past disease outbreaks are reviewed in order to identify social science 'entry points' for emergency interventions and preparedness activities. This evidence will come together to determine tangible ways to better address the social, political and economic dynamics of epidemics; and to ensure that interventions build on the social and cultural resources of the communities they aim to support. This report explores lessons about the social dimensions of past and recent Ebola epidemics, highlighting recommendations for future responses.

1. History and tradition matter, but people will learn and adapt if supported

Approaches to disease control should be based on the recognition that communities have the capacity to learn and adapt to new circumstances. Many communities have developed approaches to distinguish between epidemic and 'normal' illnesses and to adapt their behaviours accordingly. This means that they have important insights and experiences when it comes to responding to outbreaks, including cultural understandings and practices which can work in parallel to biomedical rationales and interventions. Through their first-hand experience of the disease during the outbreaks, communities' own learning and behavioural change can turn the epidemic around, particularly so when supported by the response.

- In practice, this means settings up participatory, solution-focused, consultations with affected people during Ebola epidemics. Response actors should operationalise social science intelligence from affected communities, groups and people to improve the effectiveness of the response. Information should not just be collected, but most importantly, be acted upon.

2. Predictions about the emergence of Ebola are contested and should be viewed critically

Bats are thought to be the host species but this has not been confirmed. Ebola emergence is the result of complex human-ecological interactions which are difficult to predict and have been misunderstood in the past. Bat-primate-human-forest interactions are influenced by climatic, socio-economic and ecological pressures, an understanding of which requires the integration of multiple disciplines and of local expertise.

- Research activities (e.g. modelling) aiming to understand changes in forest ecosystems and predicting future Ebola outbreaks, must work at different levels:
 - (i) incorporating input from different academic disciplines (e.g. biological and medical sciences as well as anthropology and history): incorporating not only genetic and medical surveillance, and ecological dynamics, but also transformations in social structures, land-use and human behaviour.
 - (ii) capitalising on the knowledge of local communities in forest areas and how they perceive changes in wildlife and the environment, cognisant of changes in animal consumption, human movements and trade and deforestation, as social interaction with the emerging ecological risk is key for attempts at prediction.

3. Focusing on bushmeat consumption as part of a response can be counterproductive

Bushmeat is potentially a source of Ebola infection; for example, the virus can stay active in the carcass for at least four days, so contact with an infected carcass during hunting and butchering could lead to infection. However, cooking kills the virus. During a response to an outbreak the emphasis is often put on 'spillover' (i.e. when the disease jumped from animals into humans) via the consumption of bushmeat, resulting in messaging and regulation to discourage its sale and consumption. However, after the initial transmission to humans, the most common form of transmission is person-to-person contact. The focus on bushmeat is detrimental when it overshadows more important and accurate messages about transmission; and especially because it can arouse suspicion as it contrasts with people's positive experiences of eating bushmeat. Messages should change once an outbreak has occurred, transitioning towards to risk behaviours in human-to-human transmission. Otherwise, this can undermine people's overall trust in the response.

- Spillover and human-to-human transmission should be clearly distinguished and explained in outbreak response.
- Unless the emerging epidemic has multiple cases of zoonotic spillover (rather than just one), bushmeat consumption should receive less attention than human-to-human transmission.
- Identify who is involved in hunting, butchering and trading bushmeat and seek their involvement in adapting local hygiene and consumption practices as part of prevention and preparedness, and prevent these people from being blamed for the epidemic.
- Seek voluntary compliance, and understanding around the different types of meat that can and cannot safely be consumed, rather than enforce 'bushmeat market bans'.

4. Local categories of health and disease provide important clues to the circulation of disease, people and rumours

Effectiveness of the response can be enhanced by working with communities and through their cultural worldview. Cases should be defined through local language and context. Surveillance and identification of Ebola outbreaks can be improved by the incorporation of local understandings of disease e.g. categories of symptoms, how unusual events are identified and labelled. Often biomedical and social interpretations (e.g. witchcraft, government conspiracy) coexist and engaging in a dialogue with communities early in the outbreak helps to prevent rumours and resistance. It is important to understand how the epidemic and the response to it (e.g. specific activities such as contact tracing and the intention of the people carrying them out) is perceived by communities and how this is informed by past experience and local political and cultural logics (e.g. armed conflict, corruption, conspiracy, marginalisation, limited (health) education). Understanding family structures and local social order, and how that translates into responsibilities for care and burial, will help to predict where a patient or a body might be moved and who by, and therefore spread of disease.

- Surveillance, testing and contact tracing require immediate engagement and support from the affected population. Involve locally respected and trusted leaders to negotiate access and support for contract tracing, surveillance and other activities.
- Local categories of illness and methods of identifying unusual events should be incorporated into surveillance and response operations e.g. community based surveillance systems.
- Determine local social structures and associated gender and age obligations for information on who cares for Ebola patients and bodies and where they are cared for.

- Involve local communities in mapping patterns and categories of population movement to trace and prepare for potential transmission to secondary sites.
- Set up participatory, two-way citizen feedback mechanisms that can provide real-time intelligence on the circulation of disease, people and rumours.
- Rapid evidence reviews of existing literature can also help predict key challenges for the response and help find solutions for bottlenecks that the response may or may not face.

5. The empirical observations of communities about disease transmission must be taken seriously

New knowledge will be formed based on observations from first-hand experience, blended with past experience and available public health information. People will come to their own conclusions based on what they see around them, e.g. if a contact tracer visits a neighbour, and on how well such activities are explained.

- Transparency is paramount and response workers should explain what they are doing and why, both to those immediately affected and to the surrounding community.
- Communication at a local level must engage with people's first-hand experiences (what they see of who is affected and who is not, who is interviewed and who is not).
- Citizen concerns should be adequately addressed by engaging in open, constructive two-way dialogue with the affected populations. It is important to address misinformation that is being spread about the virus.
- The response should note that they are not the only communicator, and particularly in conflict-affected areas, a close eye should be kept on negative, counter-narratives that create fear and fuel resistance towards the response. The population should be educated on the difference between 'fake' and 'real' news and reporting.

6. Activities most likely to transmit Ebola are often those which are deeply social and psychologically meaningful

Some of the most 'risky' activities, such as caring for the sick, or washing the corpses of loved ones before burial, are emotionally powerful and central to the social fabric. Failure to do these can carry high social and spiritual risks e.g. disrespecting the dead, jeopardising social and natural orders. Preventing people from performing these activities can lead to resistance and must be sensitively managed. These activities and understandings may become all the more significant during Ebola outbreaks, and could lead to alternative explanations of transmission, for example: retribution of ancestors, spirits, transgression of social norms, or witchcraft and sorcery. On occasions, these alternative explanations may entail positive practices from the point of view of public health (e.g. isolation of people with symptoms) as well as negative (e.g. stigmatisation).

- Identify practices that involve close contact with sick people and seek the meanings and social goals attached to these practices. Recognise potential crossovers between alternative explanations of transmission and public health objectives (e.g. community-based quarantining and movement control) as a basis for cooperation.
- Understand the different local causal explanations for Ebola illness and transmission including (i) how the disease is identified through signs and symptoms, (ii) the cause, (iii) transmission (iv) risk groups, (v) how it kills, (vi) necessary treatment, (v) prognosis and (vi) prevention.
- Rather than refute alternative explanations it may be more productive to work with or in parallel to them while managing the social consequences (e.g. stigma or marginalisation) that may arise.
- Appropriate mental health and psychosocial support considerations should be integrated in all response activities. Each pillar should have clear guidance as to how MHPSS is included. Key psychosocial principles including hope, safety, calm, social connectedness and self- and community-efficacy should be embedded across every

intervention. A key area in which psychosocial expertise is required is to ensure that burials are not only safe but also dignified.

7. Vulnerability for Ebola infection is shaped by gender, age, social roles and contextual realities including access to treatment

Likelihood of infection or death involves separate dynamics. Among others, vulnerability to infection is shaped by gender, age and social position as these determine responsibilities in the care of the sick and burial practices. Vulnerability to death is likely to be increased by remoteness from or inability to access health facilities, while income shapes access to treatment. Health staff are at high occupational risk especially where sanitation and protective equipment is limited; infections among health workers and within hospitals can amplify the epidemic.

- Identify the social distribution (e.g. age, gender, ethnic, social, professional group, etc.) of practices which involve close contact with the sick and dead e.g. care and body preparation for burial, transport of the body, etc.
- Training for healthcare workers on Ebola and appropriate biosecurity should take place at the earliest possibility during an outbreak and should include practical recommendations.
- Vulnerable groups should enjoy extra and specific protection from response actors and information and education material should be tailored to fit their communication needs and preferences.

8. Voluntary compliance and decentralisation of key activities to communities is more useful than coercion

Ebola outbreaks have shown communities' capacity to modify burial practices, organise movement control and quarantines, and manage community Ebola care centres. In the West African epidemic in 2014-2016, when local communities were in charge, self-imposed quarantine was crucial to control Ebola, it reduced breaches of quarantine and aided in contact tracing and identifying new cases. Flashpoints have arisen when communities have been excluded from a role in managing these processes and/or forcibly subjected to control policies e.g. medical burials or quarantines.

- Establish early and maintain a dialogue between the response and communities about what is appropriate and acceptable care. There should be an openness to cultural difference, historical precedents and to workarounds based on them. Relevant solutions that respect Infection, Prevention and Control (IPC) protocols, and address the spread of the virus, should be co-constructed with affected population.
- If using restrictive tactics such as quarantine or patient isolation, prioritise community-management. Ensure that people have their practical concerns met e.g. food, water, appropriate basic equipment (bucket, drinking glass for the patients), travel money, information as well as psychosocial resources.
- Channel resources and responsibility towards the local management of key disease control activities (in particular safe burials), ensuring it includes training on safety and equipment for implementation.
- If insecurity makes it challenging for response actors to reach affected communities, it is important to set up alternative communication structures including for example social network or mobile phone platforms. Failing to directly communicate with the affected population about response activities can negatively impact perceptions of the response and result in resistance towards the response and fear.
- With vaccination activities, particularly with vaccines that have not been licensed, it is important to set in place proper consent mechanisms and clear communication strategies before, during and after the response.

9. Change in practices requires material resources and sustaining the significance of social practices

Communities are more likely to change practices in care and burials, provided that risky practices are replaced by ritually and emotionally meaningful equivalent safer practices. For example, safe and dignified burials that meet the social, psychological and spiritual needs of the community and the family, or treatment facilities that allow for kin and community meeting their obligations of care and companionship towards patients.

- Co-develop protocols with affected populations. These protocols should contain a degree of flexibility and align as much as possible with existing practices. Keep guidelines, e.g. on safe and dignified burials, as close to funeral practices as possible, only removing or changing components that are medically unsafe, and including provisions for discussions around any adaptations or replacements made.
- If handwashing is recommended, it should be made sure that communities have access to water, particularly for vulnerable and marginalised groups including refugees and IDPs living in informal and tented settlements, in often very unhygienic conditions.

10. Promoting behavioural change has been successful with support of influential and trusted members of the community

In the West African epidemic, partnerships were established with local administration and customary authorities, religious and community leaders, as well as other socially influential individuals according to their social roles and cultural context (e.g. traditional healers, midwives, traders, and heads of local societies). These individuals acted as intermediaries and in a sense, as translators between the response and the communities. This aided in generating voluntary compliance to public health measures and helped mitigate rumours about treatment units and community care centres and the response.

- Seek partnerships with relevant local authorities: local elites, health system authorities (national, provincial, district and zonal), administrative authorities at all levels, customary authorities (e.g. chiefs) and socially significant individuals in the area (e.g. teachers, healers, midwives). Utilise these partnerships to address negative, counter narratives that spread fear and distrust amongst community members.
- Mobilise trusted local community members for community engagement and other response activities. A quick survey with a cross-section of society at the onset of the outbreak will serve to see who is trusted in the community and will show inconsistencies between official and self-proclaimed 'leaders' and trusted people.
- Pay attention to the voices, the communication needs and preferences of marginalised groups, who might not be automatically included in response activities. Ensure the inclusion of their leaders and local role models part of these marginalised groupings.

11. People will seek healthcare from a whole variety of providers, and engaging these providers will increase the effectiveness of the response

The response should work with alternative providers, seeking referrals and cooperation, rather than in competition or banning them. People are pragmatic in seeking care, they will try different courses of action to find a cure and their choice will be informed by past experience of providers and notions of quality (e.g. if the staff were kind or if they had to pay for services supposedly free). People often seek biomedicine and 'traditional' or faith medicine consecutively or in parallel influenced by issues of cost and access as well as local health beliefs. The preferred health-seeking behaviours and choice of providers will depend on the context, and may include: home-treatment, visiting clinics or health staff within personal networks or preferred by them, seeking help from traditional healer or herbalists, faith healers, drug vendors and so on. Note that whom people appeal to for care may shift over the course of an epidemic.

- Understand who the relevant health-providers are in the current context and what their models of disease and treatment are (drug sellers, traditional healers, faith healers, and so on). Health-seeking behaviour may differ per groups in a certain community and the response needs to be cognizant of the complexity of the local situation.
- Engage with providers early on, harnessing their influence rather than resisting it. These healers can be enlisted for Ebola messaging, to support surveillance and encourage referrals to biomedical clinics or community care centres of Ebola patients. Give these health providers information on transmission and risk behaviours and distribute protective equipment.
- At the same time, it is critical to map barriers to accessing traditional and modern, private and public healthcare facilities and services, particularly in conflict-affected areas. Barriers to care should then be addressed by the Ebola response team, perhaps making use of mobile clinics or testing facilities.

12. Consider treatment facilities which are located closer to communities, or ensure there are communication links between patients and families

Community-based care proved successful in the West African Ebola epidemic and can be in line with existing local response to epidemic emergencies. Setting such facilities up and employing community members allows trusted people in the community to make decisions about care and it allows for local adaptation of practices to local needs (as long as they meet public health goals). It allows a closer information flow between care centres and households, and avoids the rumours and misinformation that emerge when patients are taken to faraway clinics.

- Decentralise care as much as possible if the communities are willing (and this has been often the case), including training and enabling communities to manage triage, quarantine and treatment in community care centres. Make sure that proper and fair remuneration is provided for actors involved in such initiatives, even if communities offer their services voluntarily.
- Wherever they are located, Ebola care centres (treatment units and community care centres) must be sensitive to the caring needs of patients and their family members, e.g. allowing for visits of relatives and friends in a safe manner, have systems in place for people to get in touch with families (e.g. phones, post), and that the wider community is educated on 'what goes on' in the Ebola units to avoid scepticism and fear around treatment.
- During large epidemics, or in unsafe war-torn areas, when formal treatment options are limited, give households the practical skills, recommendations and material resources (personal protective equipment and other relevant equipment) to carry out home care of patients – although not ideal it is likely to occur anyway. Options for remote support and trainings (on for example, safe burials or emergency, community-based care) could be explored (if financially and logistically viable) making use of social and other new media including WhatsApp video.
- Establishing community emergency plans and emergency funds (e.g. establishing who pays for transport and food, where quarantining can take place and so on) may help in preparing communities in advance for an outbreak.

13. Burial protocols should incorporate the needs of the social group, community and family

Burials have to be simultaneously safe, dignified and meaningful. Burial and funerals play a social role as much as a practical role of putting a body in the ground. For example, in burial practices in parts of West Africa often include procedures to distribute inheritance and ensure the deceased an afterlife. Failing to conduct funerals appropriately may cast family members as negligent, or foster suspicion. Burials and funerals also play a psychological and emotional role, as an important part of a grieving process. Social

structure, culture and religion determine who washes the body and prepares, dresses, and decorates it for the wake and burial. There is a high variability of burial practices within African countries, and there is a need for a detailed discussion about risk prevention in each context to identify which practices are risky i.e. body preparation versus attending a funeral. Communities are the best placed to suggest acceptable modification to funeral practices. A degree of personalisation that allows for status recognition and commemoration limits resistance. The process of personalising the burial may also help remedy the psychological and emotional loss of the 'normal' burial process, although this needs to be further studied.

- Adapt burial practices to the specific practical, emotional and symbolic needs of the affected family/group and wider community, as a product of a negotiation between burial teams and the affected family.
- Whenever possible, relevant, and desired by the family, provide safe transport and burial of bodies to their home villages, and provide families with the option to pick the place of the grave (e.g. beside their house, in the forest, etc.).
- Create an opportunity for the family and other important, selected members of the community to visually view the body in a safe manner from a distance. This will help curb rumours around the 'stealing of bodies' and suspicion in the response which can cause fear and resistance against IPC measures. It would be useful to explore the use of transparent body bags for the Red Cross ambulances or have a member of the family/community travel with the ambulance to discuss with other communities, who may have concerns.
- Families of suspected, probable and confirmed cases should be sensitively (and in a timely manner) informed about what will happen in the event that their relative dies. The safe and dignified burial procedure agreed at the local level should be carefully explained, and opportunities provided for the family and the wider community to ask questions and make particular requests. This will avoid the risk of surprise, suspicions and incorrect assumptions, and is likely to play important social and emotional functions as described above.
- Burial teams should include persons who already customarily play a role in death, burial and funerals and who are known to local communities (for example, religious leaders or traditional healers and leaders). Such individuals should receive training on safe and dignified burial protocols and procedures and should act as liaison between a family and burial team, even if they are not directly involved with making the body medically safe.

14. Trust can be built through communication approaches that respect local perspectives and are in tune with local contexts

The quality of community engagement is as important as risk prevention messages. Messages need to be accurate, understandable, practical and relevant. Messaging needs to be tailored to the available infrastructure, i.e. pushing people to wash their hands where there is no clean water points available, or separate cups for each patient when there are not enough to go around, can leave people disillusioned. Mistrust and stigma is likely to arise in Ebola outbreaks along existing fault-lines: ethnic or other social groups accused of being carriers of the disease, or individuals singled out: survivors, health workers, and in some contexts people who might be accused of witchcraft e.g. street children or widows. However, this can be combatted by sensitive messaging based on contextual analysis of vulnerable groups.

- Employ community engagement methodologies, which give communities a voice, and a chance to be listened to. Establish two-way, participatory channels of communication between the response and communities discussing beliefs and prevention measures, acknowledging that these are fluid and change over time. Give affected populations

- the ability to ask questions and solutions to challenges, and act on the information provided.
- Accurate, relevant and practical messaging, that takes into account local understandings of the disease and practical everyday challenges. Messages should offer practical, actionable recommendations, framed in positive terms, and conveying hope and a sense of ‘togetherness’, and should be provided in the local language(s). Engage specific social groups within communities directly whenever relevant (e.g. women, indigenous people, young people).
 - Mobilise trusted community or social group members for community engagement. Ask a cross section of the community who the affected population trusts and check for inconsistencies between official and self-proclaimed ‘leaders’ and nominated trusted people. Survey in parallel, the communication needs and preferences (language; preferred format; delivery method, etc.) of the different social groups affected.
 - Ensure recipients of messages have the resources needed to adhere to advice given e.g. bucket, cups, disinfectant, protective equipment, etc.
 - Identify who is at risk of being stigmatised during the Ebola outbreak and monitor this, developing messages or support to counter stigma.
 - Communication efforts should evolve with the spread of the disease and the response, acknowledging the interaction between both the response and the communities’ learning processes and the stages of the epidemic: approaches and messages will vary.
 - In terms of communication around vaccination processes – information should be provided around the vaccination process but also around the meaning of ‘being part of a trial’, ‘what consent means’ and what remuneration is or is being provided for participants of the trial. Consent will be negotiated both from individuals and communities, to ensure the vaccination trial has broader support. The consent procedures should be designed to fit the communication and information needs of the affected communities. This might mean translating the consent procedures into the local languages, making use of visual communication and reading the consent procedures aloud rather than giving the paper to the patient to read.

15. If Ebola breaks out in a conflict affected area it is important for the response to continue to be perceived as neutral, whilst addressing the politicisation of the outbreak

In conflict-affected areas, local governance structures have often been weakened by mass violence and killings. Ready-made authority mechanisms and trusted networks are often inexistent or difficult to access, which can create barriers to an effective response. Chronic insecurity, episodes of violence and the political backdrop can influence how communities construct and interpret different narratives. The risks of politicisation of an outbreak and the response must also not be underestimated.

- Conduct a rapid political economy assessment to get a handle on important alliances, institutional rifts and other geopolitical challenges.
- Do not assume that international agencies are perceived as neutral and impartial. Apply such clear visual markers so people can quickly and easily distinguish personnel and vehicles associated with the Ebola response.
- In any conflict-affected area, there is a significant risk that the outbreak and the response will become politicised and that factions at both the national and provincial level may use it according to their own agendas. High levels of distrust between different sections of the population can lead to scepticism about both the virus and the response.
- Distrust contributes to on-going practices that heighten the risk of transmission, issues around vaccination, widespread community dissatisfaction, and incidents of escalating violence against response teams.

- Working in conflict-affected areas may have severe ramifications for response actor's ability to move and reach affected areas. If access is an issue creative solutions should be designed to still reach the affected areas including via new technologies including WhatsApp, social media or drones.

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