

Summary: 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 preparedness and response activities. This brief draws out some recommendations for Ebola response actors in North Kivu. It includes lessons learned primarily from (i) historical outbreaks in Congo; (ii) outbreaks in Uganda in 2000-01 and 2012; (iii) the 2014-2016 West African epidemic; (iv) the outbreak in Equateur Province in DRC (May- July 2018), and (v) the ongoing outbreak in North Kivu and Ituri Provinces in DRC (August 2018 - ongoing). The full report can be accessed here: <https://opendocs.ids.ac.uk/opendocs/handle/123456789/14160>.

Cross-pillar recommendations

Our evidence synthesis highlighted various cross-cutting trends that apply to all response pillars:

- Communicate openly, frequently and transparently by using trusted local media and interpersonal engagement to affected communities about the outbreak: who is affected and what the government, international and local partners are doing to protect the community. Acknowledge and empathise with frustrations and fears. Establish constructive dialogue that seeks mutual improvements and takes into account community feedback in response activities together with affected communities, neighbourhoods and families.
- Actively listen to the concerns of affected and at-risk communities. First-hand experiences of the response can be crucial: perceptions of "who is visited", "who falls ill", and other observations by communities may lead to inaccurate ideas and fears. To avoid misinformation, ensure transparency and constant two-way dialogue with communities. Compassionate communication across all pillars is key.
- Collect community feedback and act on solutions provided by affected people, whilst being honest about what government and response partners can do (e.g. compensation of belongings destroyed during decontamination) and the limitations they face (e.g. having insufficient funds to build ETC's in each village).
- Work through existing health and other social service actors and local leaders that affected populations use and trust – medical doctors, nurses but also local healers, pharmacies, teachers, community leaders, women and youth groups, etc. This will build confidence in the response, support reach of interventions and encourage timely utilisation of services.
- The response must identify vulnerable groups who are at risk of harm and may be left out of the response (widows, orphans, street children, people with disabilities, etc.) at an early stage and set up strategies to protect them.
- Voluntary compliance and decentralisation of activities to communities is more useful than coercion. In the past, forced compliance to follow protocols has resulted in increased community resistance and mistrust.

Surveillance and contact tracing

Surveillance, testing and contact tracing require immediate engagement and support from the affected population. Transmission is significantly determined by social factors: who cares for the sick, where and how; who prepares, transports and buries bodies; the ceremonies people attend; the usual migration routes people follow, etc. Contact tracing and surveillance teams should:

- Identify local categories of illness and methods of identifying unusual events and incorporate them into surveillance operations e.g. community-based surveillance systems and ask communities what alert systems would work best for them.
- Operate in a respectful manner when entering an affected community including ensuring the privacy of affected families and communicating any delays in the provision of response activities. Response teams need to be aware of local customs, language and dialects and interpersonal communication skills that are rooted in empathy and respect.
- Harness the knowledge of local "guides" (for example, family members and local leaders) when establishing lists for vaccination and contact tracing activities, and explain why these lists are created and how they will be used.
- Carry out participatory research on population movements (routes; underlying ethnic, social and economic ties). It is important to understand the practices and particularities of different social groups to understand their risk profiles, and to triangulate socio-behavioural knowledge with epidemiological data.
- Address concerns about the length of time it takes to report on laboratory tests by communicating why delays have occurred. Seek local solutions to ensure the flow of timely information.

Case management and Infection Prevention and Control (IPC)

Activities designed to prevent and control infection may require short-term yet significant changes in behaviour and material resources that are not always available, desirable or understood. Such measures can evoke fear and mistrust. Activities most likely to transmit Ebola (e.g. burial rituals that include preparing bodies; caring for the sick without protection measures) are both deeply social activities and psychologically meaningful. As such, the response should:

- Set up participatory action-oriented sessions with at risk communities to prepare for the eventuality of an Ebola-related incident in their community, including the establishment of community preparedness plans.
- Ensure that affected communities/neighbourhoods have the means to follow the IPC measures that are being promoted, including providing handwashing stations or identifying safe, locally available alternatives.
- Consider the decentralisation/devolution of care to community care centres or even home care in certain circumstances, for example when locations are out of reach to the response due to security constraints. Community care centres were used during the West African outbreak and successfully provided triage and basic services at the community level.
- Carefully consider the fears that exist around Ebola Treatment Centres (ETCs). Supportive communication and negotiation with affected communities is needed to "demystifying" treatment facilities. This can be done by: enabling communication between ETC patients with their loved ones who are "on the outside"; providing funding for transport so families can visit their loved ones and be involved with their care through bringing food packages and providing psycho-social and emotional support to patients and families. In this regard, the ALIMA Cubes appear to have been particularly well received in the DRC. It is also important to provide information on care to the wider communities as well as those who are directly affected. Inviting community leaders, traditional healers and other "key influencers" to visit the ETCs, allowing

them to “see with their own eyes”, providing them with key information to share with their communities and encouraging them to advocate that people seek timely care at facilities has led to positive affirmative action in past outbreaks.

- Involve survivors and ETC staff in discussions around care procedures. Fears and misinformation that may arise (e.g., organ harvesting, fear of death, isolation or inappropriate treatment) should be addressed through channels including on-going community and interpersonal dialogue, outreach activities, and the media. Support and protect survivors and ETC health care workers, making them feel appreciated whilst performing this important public service.

Risk communication and community engagement

Behavioural change, care and treatment uptake has been successful with the support of influential and trusted members of the community, but actors should continue to be responsive to the suggestions of affected communities and act on local solutions. Trust is built through two-way communication approaches that respect local perspectives and deepen transparency.

- Understanding local power dimensions is important and it is important to communicate with neutrality. Investment must be made in efforts that deepen transparency and accountability. Working with local journalists can help counter narratives that create fear, perpetuate misinformation and fuel resentment towards the response. Affected populations should be supported to understand the difference between “fake” and “real” information and news.
- Social, communication and contextual data along with participatory action data should be used to develop communication approaches and messages that promote preventive, treatment-seeking and care behaviours building on local context.
- In past outbreaks as well as the current outbreak in DRC, it has been necessary to reassure the public that the provision of free care during the outbreak will not undermine its quality, explain how quality of care is maintained and IPC measures. Rather than just instructing people about what to do in a didactic manner, explanations should be offered about why protective and preventative behaviours are important.
- Strategies to mitigate community reluctance and potential hostility towards the response, may include participatory, community-based activities and negotiation. Action-based workshops that use ‘edutainment’ methods and roleplay have been well received. Multiple platforms should be employed strategically to create the greatest impact.

Vaccination and therapeutics

History, trust towards health authorities, first-hand experience, and community perceptions of notions of strength, risk and immunity shape uptake. As such, fairness in selection and clear communication regarding to whom the vaccine is offered, why and when is key.

- Initiate community mobilisation before the start of a vaccination campaign/trial to avoid negative associations. In the context of vaccination in the current DRC outbreak, it is important to convey detailed explanations about “ring-vaccination”, why it is the method of vaccination, who is included/excluded and why, and how the whole community benefits.
- Consent should be negotiated from both individuals and communities; secure broad community support for vaccination and investigational therapeutics. Consent procedures should be tailored to the local context and fit the information needs of the affected communities (consent should be done in local languages, and could make use of visual communication aids).
- Longer-term support to individuals and the broader community is needed after the outbreak, particularly in relation to vaccination and the use of trial therapeutics. Affected individuals and community members should be supported to know their rights and obligations, to be able to discuss longer-term results or adverse effects and to have their questions answered and concerns addressed to their satisfaction.

Safe and Dignified Burials (SDB)

Safe and dignified burial protocols must be tailored to the local context to ensure that the symbolic and emotional significance of social practices remains intact. This is best negotiated at the local level with communities and trusted leaders, and tailored to family needs.

- Communities are best placed to suggest acceptable modification to burial and funeral practices. A degree of personalisation that allows for status recognition and commemoration reduces potential resistance. Whenever feasible, families should be allowed to select the grave site and follow local customary. If appropriate, safe transport should be provided to enable the burial of bodies in their home villages or ancestral land.
- Challenges often result due to the length of time that elapses between when a family calls for a burial team and when they arrive. Give community members accurate information about how long it will take for a team to arrive and what family members can constructively do during this period. First responders and burial teams should be trained in compassionate communication and psycho-social support approaches, and be able to appropriately negotiate with the grieving family.

Mental health and psychosocial support (MHPSS)

Activities most likely to transmit Ebola are those which are deeply social and psychologically meaningful:

- Integrate appropriate mental health and psychosocial support considerations in all activities. Each pillar should have clear guidance as to how MHPSS is included. Key psychosocial principles including hope, safety, calmness, 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 and that affected communities are offered on-going psychosocial support if SDB is perceived to not be a ‘proper’ burial.

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