



5 EVIDENCE-BASED LESSONS FOR EFFECTIVE COMMUNITY ENGAGEMENT IN EBOLA VIRUS DISEASE RESPONSE

The following five lessons have proven impact during previous Ebola Virus Disease (EVD) response. These lessons help us put communities at the heart of the response, making it more effective, timely, relevant, and ultimately contributing to promote trust and community action.

LESSON 1: Community Engagement is not about ensuring community acceptance of response interventions, but rather adapting response interventions with communities based on their needs, feedback and context.

It is only through adapting response approaches to and with communities (based on their context and realities) that they can be successful in contributing to ending the outbreak. There is a misconception that we want to understand communities to get them to “accept” and “adhere” to response interventions. Using evidence and working in partnership with communities means adapting response interventions, making sure communities participate in the co-creation of recommended public health and social measures. The burden of responsibility is on humanitarian responders and health providers to adapt response interventions and services so that they are safe, accessible, and appropriate to context and not on communities to ‘accept’ interventions.

EXAMPLE in practice

Part of stopping the outbreak requires successfully identifying and following all contacts. When response interventions impose rules on individuals, this can

create fear and distrust and result in the individual running or hiding from the response which in turn can increase the overall risk of transmission. Safe burials are crucial for preventing transmission. However, when preferred burial practices are not considered, community distress and anger can result, leading to reduced community engagement in response activities.

In eastern DRC, for example, at the start of the 2018 outbreak the DRC Red Cross was refused permission to perform 79% of Safe and Dignified Burials (SDB). When volunteers scaled up community participation in SDBs, allowing family members to participate safely in the burials, the rate of successful SDBs increased to 92%.

HOW this can be done

It is key to training response teams to engage communities in all we do. Response teams such as Safe and Dignified Burial (SDB), laboratory testing teams, Infection Prevention and Control (IPC), surveillance, and Risk Communication and Community Engagement (RCCE) as well as community health workers and volunteers need to learn how they may need to adapt interventions **to ensure an individual or community's participation in outbreak control.**

¹ These lessons are based on evidence and research done by the Integrated Outbreak Analytics in DR Congo.

Using scenario-based trainings can help. **The following are some of the critical questions for response teams to address during trainings to ensure an adapted response:**

- Do SDB teams know, and can they explain all the ways the families can participate in the burial?
- Do laboratory testing teams see opportunities to allow a local/trusted healthcare worker to do a test if it will lead to improved testing participation?
- Are surveillance teams willing to let someone in the family support contact follow up to facilitate continuity of surveillance activities?
- Are Ebola Treatment Centre (ETC) set up to create access for families to communicate with patients? Are response teams explaining this information to communities?
- Do RCCE teams know how to establish systems and platforms that allow communities to voice their understanding of the issues, questions about the disease and suggestions about the response?

LESSON 2: Focus Risk Communication and Community Engagement efforts on the most critical behaviours to control the epidemic

The most common preliminary symptoms of EVD are muscle ache, back ache, fever, nausea, and headache. These symptoms are also common symptoms for influenza. **During an Ebola outbreak, we're asking individuals to seek care and get tested for symptoms that they normally would treat on their own.**

Posters, imagery, and communication (as well as surveys testing "knowledge") of symptoms which focus on "wet" symptoms (bleeding, diarrhoea, and vomiting) have been found to reinforce high-risk behaviour. Also, previous outbreaks have found low understanding of how contact tracing works and reasons why people's names are written down. This created fear and suspicion. Finally, evidence from previous outbreaks revealed the need to better explain how safe and dignified burial is conducted.

EXAMPLE in practice

In the 10th EVD outbreak in DRC, posters, imagery, and communication which focused on fear-based messages, such as "Ebola kills" and the severity of the disease ("wet" symptoms such as bleeding, diarrhea, and vomiting), resulted in feelings of helplessness and fatality and were found to reinforce high-risk behaviour: (1) delayed treatment seeking; (2) distrust in EVD diagnosis; (3) unwillingness to accept a Safe and

Dignified Burial (SDB).

HOW this can be done

It is key that all response workers can explain the first signs and symptoms of Ebola and that communication is clear that the "behaviour change" is temporary to ensure that we identify cases early to save lives.

Messages focusing on "early-treatment seeking saves lives" in the DRC outbreak eventually contributed to shorter delays in treatment-seeking, resulting in greater survival rates. It is also key that response teams support with communication on the key behaviours, such as early treatment, contact tracing, SDB and vaccination (when available) and all frontline workers can explain those easily. Also, in DRC and Guinea, the response teams used a video kit that explains contact tracing, safe and dignified burial, and other videos to show how an ETC looks like.

LESSON 3: To build trust, we need to listen and then to act. Asking questions is not resistance.

Encouraging questions, feedback and responding with knowledge and willingness to course correct action, rather than focusing on encouraging "acceptance" of the interventions without explanation, will increase community trust in the intervention.

Community feedback mechanisms will help collect critical information on key questions, concerns, beliefs and suggestions raised by different community groups and in different locations. Messages (via response teams, radio etc.) and response activities should be adapted weekly to respond to the feedback topics with sufficient detail. Labelling misunderstandings as rumours dismisses an individual's reality and beliefs and can be stigmatizing. Understanding where these "rumours" came from and tackling the root of the misunderstanding with the right information, through respectful dialogue, is key to improving trust and response impact.

EXAMPLE in practice

Ebola vaccines have the virus in them" was labelled as a rumour in DRC. However, previous polio and other vaccination campaigns in DRC have explained concepts of live attenuated viruses and antibodies to communities.

Although the Ebola vaccine (for the Zaire strain of the virus) does not contain live attenuated virus, as is the

case with oral polio vaccine (OPV), a failure to provide information on how the Ebola vaccine worked resulted in this “rumour” rather than a critical belief based on their understanding of vaccines.

HOW this can be done

Ensure sufficient training and regular briefings of response teams to listen to communities questions and concerns and provide appropriate answers to communities. It is critical to **create a space where response teams can, at the end of each day, find answers to the questions they did not know**. It is critical that they are trained to say “I don’t know, I will follow up and get back to you” rather than to respond with false information. Training and support to teams must be ongoing, as understanding of Ebola, associated vaccines and treatment can change during the outbreak. Communicating that some things are not known is key, shows honesty and increases trust. Developing a Q&A sheet for response teams and volunteers can be a useful way to centralise answers that might be needed.

LESSON 4: Be aware/understand gender-dynamics of access to information, decision-making and participation in community engagement activities.

Communication plans need to reflect community priorities and preferences by location and social group. Studies often ask most preferred and trusted sources of information and yet, those are most often not where information is made available. Understanding trusted, preferred, and accessible sources of information should guide strategies.

EXAMPLE in practice

Sensitization and community engagement activities are often placed on women. Women are generally expected to be at home “receiving” information (e.g. door-to-door visits) and are then expected to take action or “sensitize” or raise awareness as community volunteers. Yet women have limited decision power, are more likely to be illiterate, and therefore less likely to find paid employment in an outbreak response and already have the greatest burden of unpaid care.

HOW this can be done

Outbreak response activities must reconsider meaningful and compensated roles for women within the response.

Men and women have different access to information; quality information needs to be made available across media which are accessible to both (e.g., videos in local language can be better understood by all compared to printed word, however videos shared via social media may be more accessible to men who may be more likely to have smart phones).

In addition, in DRC recurring feedback from communities asked for more local people to lead the response. Hiring local staff and empowering them to make decisions means your response speaks the right language, understands the context and can build trust more quickly. As the balance of the Red Cross team shifted to be more local, it has improved our access, acceptance and relevance.

LESSON 5: Collect and use data for decision making and course correction under an integrated outbreak analytics (IOA) approach

It is key that data collection is done together with other actors in the response and that data collected are usable and used. Collecting generic information on disease perception may not provide us with accurate or actionable evidence. Before collecting data we need to ask ourselves *what do we want to know? What is the best method to get this information? How will it be used and by who?* Data should be analysed in an integrated manner, providing a comprehensive understanding of outbreak dynamics and is led by the response coordination.

EXAMPLE in practice

Common mistakes in data collection by RCCE:

- **Hypotheticals:** “would you accept a vaccine”: we cannot act on this, because we do not know why or why not; also, hypothetical is influenced by many factors (perceived access, availability, risk, real access, behaviour of others etc. And may change based on proximity to the disease).
- **Analysing data by “top 3”:** if 90% of the population know 3 symptoms of Ebola, but they do not know the symptoms which are the most common; or we do not know which symptoms illicit healthcare seeking – this data is not usable,
- **We “exotify” community behaviour** (e.g., burial practices) that don’t require large anthropological studies – simply asking individuals their preferences (as in any part of the world) and adapting accordingly.

REFERENCES:

- What is Integrated Outbreak Analytics (or IOA)? <https://www.youtube.com/watch?v=ZC0hZr2YVpM>
- IOA is a Multi-Actor and Multi-Discipline Approach <https://www.youtube.com/watch?v=31tla7X7Zyk>
- IOA approach for decision-making in public health emergencies <https://www.youtube.com/watch?v=RyU9fsGYBcE>
- RCCE Collective Service Africa - [Finding community-led solutions to COVID-19](#)
- [‘The response is like a big ship’](#): community feedback as a case study of evidence uptake and use in the 2018–2020 Ebola epidemic in the Democratic Republic of the Congo
- [Social Science in Epidemics: Ebola Virus Disease Lessons Learned](#)
- How to improve outbreak response: a case study for IOA <https://gh.bmj.com/content/6/8/e006736>
- Maximizing the use of evidence <https://www.unicef.org/drcongo/media/5406/file/COD-CASS-maximizing-use-evidence.pdf>

USEFULL RESOURCES:

- EVD Library <https://drive.google.com/drive/folders/1bQ5uF4ysOUIR1h9UabUpOxwMqwmMDdC8>