Social Science in Humanitarian Action

Real-Time Ebola Community Feedback Mechanism

Since the start of the Ebola outbreak in North Kivu, Democratic Republic of Congo (DRC), the International Federation of Red Cross and Red Crescent Societies (IFRC), in close partnership with the US Centers for Disease Control and Prevention (CDC), have supported the Red Cross of DRC to set up a rapid community feedback mechanism. A network of Red Cross volunteers living in the outbreak area collect rapid and regular perception data about Ebola and wider health issues of affected communities. These data inform responders about community concerns, perceptions, beliefs, priorities, and needs, and is used to tailor response mechanisms to make them more appropriate and effective.

This SSHAP Case Study provides insights into how operational social science methods of collecting perceptions of affected communities can be tailored to fit the rapid information needs of response partners and affected communities in the event of an epidemic. The IFRC-supported system can be rapidly deployed by organisations during epidemics and other emergencies to provide valuable community insights during a response, help responders recognise and address underlying anxieties, and alleviate distrust in communities and ultimately drive effective response actions. The process can be adapted by other organisations in future epidemics.
The challenge: misinformation and mistrust in the Ebola epidemic

Misinformation, mistrust of outsiders, and conspiracy theories spread quickly across affected areas in North Kivu due to decades of violence together with unfamiliarity with Ebola and response activities. As a result, the response was hampered, as fear of the unknown, entrenched beliefs, and trust challenges led to delayed notification of cases and late arrival at treatment centres. Consequently, the case fatality rate increased, and the spread of the virus was prolonged and more widespread.

In response to these challenges, the Red Cross established a system that enables communities to voice their understanding of Ebola-related issues and provide timely and regular feedback to response mechanisms. Regular collection of community feedback, including questions, perceptions, suggestions and concerns through systematic listening and monitoring is essential to informing response actions, including adapting risk communication and community engagement strategies. It helps responders to effectively engage communities in ways that specifically and timely addresses anxieties, fears, and “unhealthy” beliefs, and ultimately contributes to building trust between responders and affected communities. The near real-time perception data help first responders to understand the reasons for challenges/successes related to the uptake of biomedical interventions and allows them to adapt measures to better fit communities’ realities and needs.

The methodology: near real-time perception data on Ebola

Community engagement and accountability is at the core of Red Cross programming and operations. It is an approach geared towards putting people and communities who are vulnerable to and affected by crisis at the centre of its work. The approach encompasses a set of activities that embed and integrate participation, communication, feedback, and learning throughout programme cycle(s). It focuses on providing timely, relevant, and actionable life-saving information to communities and listening to communities’ needs, feedback, and complaints, ensuring they can actively participate, guide, and ultimately lead epidemic preparedness and response actions.

In DRC, the Red Cross community feedback system takes multiple steps:

- Over 800 Red Cross volunteers visit affected and at-risk communities around three times per week. While performing health promotion activities, they record unstructured community views in the form of rumours, observations, beliefs, questions, suggestions, notes of appreciation, and grievances.
Free-text data are recorded on paper in French and/or local languages and shared with community engagement supervisors, who provide critical translation services to and from local languages where needed. The data are then entered into Excel spreadsheets.

Local staff code data entries according to a set of themes and a defined coding system, which is outlined in an iterative coding book developed with CDC support.

Feedback data are analysed locally by using a simple Excel format to highlight overarching themes and predominant categories. CDC has been supporting by providig coaching and trainings for localised data coding and analysis. CDC also undertakes close examination of topics of interest (e.g. barriers to seeking healthcare, survivors, vaccination) and triangulates data with other existing mixed methods studies, in closed collaboration with Social Science Analysis Cell (CASS).

Analysed feedback data are shared locally per health area through simple data presentations by type of feedback (i.e. questions), themes and illustrative feedback by category (i.e. vaccine suspicions and non-acceptance). These are shared by Red Cross staff at local Ebola coordination meetings. An online dashboard supported by the United Nations Office for the Coordination of Humanitarian Affairs (OCHA) Humanitarian Data Exchange (HDX) helps with data sharing and use. The dashboard presents data summarising issues per health zone and showing trends by theme (e.g. Ebola characteristics and consequences, safe and dignified burials, etc.).

The impact and lessons learned
The intervention has so far gathered over 530,000 individual feedback qualitative data points, which makes it possibly the only such database for an epidemic response and the first novel approach to analyse qualitative feedback data in almost real-time. Strengths of the approach include:

- Information on questions or misconceptions regarding Ebola help inform and adapt risk communication and community engagement strategies, and this increases community understanding and addresses fear and mistrust.
- Analysis indicates that spikes in negative feedback preceded attacks against responders, suggesting that the feedback system could serve as an early warning function in challenging contexts.

Figure 2 Community feedback mechanism: system functioning in Phase 1
Feedback such as suggestions, beliefs and concerns help local structures and responders to adjust interventions over time based on the feedback and perceptions of affected and at-risk communities. For example, Red Cross Safe and Dignified Burial (SDB) team members use feedback data to inform changes in their approach. Adapted burial practices (e.g. use of transparent body bags so families can see their loved ones) led to a significant decrease in negative feedback on burials and increased the number of alerts communities raised when someone died. This can be taken as a proxy indication that communities started trusting teams to take care of their deceased loved ones.

Challenges with the implementation of the system were also recorded. Bringing up-to-date community perspectives to decision makers takes time and requires a coordinated effort, financial sustainability, and long-term support to build the capacity of local Red Cross chapters to roll out the system with quality and at scale, including in future health crises. Ensuring commitment from key decision makers towards tailoring services as per the requests of communities has been challenging. Perception data are often overlooked, and it takes dedicated and agile coordination to adapt approaches to each community’s needs.

In short, there has been an overemphasis on the need for communities to trust the response; conversely, it is vital that the response also trusts affected communities. Ultimately, a response will only be effective when community voices are heard and responders act on community requests and desires.

Further reading


About

The Social Science in Humanitarian Action Platform (SSHAP) aims to establish networks of social scientists with regional and subject expertise to rapidly provide insight, analysis and advice, tailored to demand and in accessible forms, to better design and implement emergency responses. SSHAP is a partnership between the Institute of Development Studies (IDS), the London School of Hygiene and Tropical Medicine (LSHTM), Anthrologica and UNICEF Communication for Development (C4D).

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