

Social Science in Humanitarian Action

www.socialscienceinaction.org

Social science and behavioural data compilation – November 2018

This rapid compilation of data analyses provides a 'stock-take' of social science and behavioural data related to the outbreak of Ebola in North Kivu and Ituri provinces. Based on data gathered and analysed by organisations working in the region, we aimed to explore convergences and divergences between datasets and, when possible, differences by geographic area, demographic group, time period and other relevant variables.

The data compilation was conducted by Kevin Bardosh (University of Florida) with support from the Social Science in Humanitarian Action Platform and GOARN Research Social Science Group. Feedback was provided by colleagues from Anthrologica, CDC, UNICEF, WHO, IFRC, and Oxfam.

This brief prepared by Juliet Bedford, Ingrid Gercama and Kevin Bardosh, serves as an overview of key findings from the data compilation. A longer working document that provides additional analysis is available from julietbedford@anthrologica.com.

Community feedback: themes and questions

Themes raised during community feedback were collated by the IFRC (with support from CDC), Oxfam and UNICEF. The table below presents the five themes most frequently identified in the community feedback gathered by National Society of the Red Cross volunteers in August, September and October (rank 1 being the most frequently raised theme). The majority of community feedback involved issues of vaccination and response processes, followed by diagnosis and treatment, Ebola vs. other diseases/problems, Ebola clinical outcomes and burials.

Themes identified in community feedback gathered by Red Cross volunteers, North Kivu 2018

	August	September	October
	233 responses	1020 responses	1896 responses
	Beni, Mabalako	Beni, Butembo, Mabalako	Beni, Butembo, Bunia, Mabalako
Rank 1	Vaccines	Vaccines	Response processes
Rank 2	Diagnosis and treatment	Response processes	Vaccines
Rank 3	Ebola outcomes	Ebola vs. other diseases/problems	Diagnosis and treatment
Rank 4	Ebola vs. other diseases/problems	Ebola outcomes	Ebola vs. other diseases/problems
Rank 5	Response processes	Burials	Ebola outcomes

Questions asked by community members were also reported as part of the community feedback gathered by the IFRC, Oxfam and UNICEF. The following is a selection of frequently asked questions as documented in the community feedback, clustered by key theme (not in order of frequency).

Questions identified in community feedback gathered by the IFRC, UNICEF and Oxfam, North Kivu 2018

Vaccines	<ul style="list-style-type: none"> Why not give the vaccine to everyone as for other diseases? Why don't pregnant and breastfeeding women get the vaccine, and yet they can be easily infected? Why do you have to show your ID card when you get vaccinated? Is the vaccine different for medical staff and the general population? After receiving the vaccine, can you touch someone with Ebola? Is money given to people who get vaccinated? Why do you take the names of the heads of household instead of marking the walls of houses as during a vaccination campaign?
Response processes	<ul style="list-style-type: none"> Why are there so many staff for the response to Ebola and not for other diseases or for conflict? . Why are doctors and nurses from our own communities not in Ebola response teams? Do I have to pay for the ambulance when they pick up a patient? Who supports the food for the patients and the communication costs for the family if somebody is in the ETC? Should we send our children to school and what precautions are being taken at schools?
Diagnosis and treatment	<ul style="list-style-type: none"> Are laboratory tests free? Is the diagnosis shared with other people? Why collect samples from the sick after their death? How long does the virus remain in the body? Why can the family not bring food to ETC patients? Is there a cure for Ebola? Why do people die when they go to ETC? Where do the medicines that are given to us in the ETCs come from?
Ebola vs. other diseases/problems	<ul style="list-style-type: none"> How can you diagnose an Ebola patient? Are the symptoms of Ebola the same as for malaria?
Ebola outcomes	<ul style="list-style-type: none"> How many survivors have there been since the beginning of the epidemic? If a mother dies of the virus, is it possible for her baby to survive? Are survivors included in outreach teams?
Burials	<ul style="list-style-type: none"> Can the family members participate in the funeral of their loved one? How do you know that the person in the bag is really dead because you do not see it? How do you treat the victim's body before burying it? Are the victims' organs removed before putting the person in the bag and burying them? Why do you not show the body of a person who has died from Ebola to their families? Why are the police present at funerals?

Community suggestions

Suggestions made by communities during feedback sessions are also collated by the IFRC (with support from CDC), Oxfam and UNICEF. The table below presents the themes of the five most frequently made suggestions made during the community feedback gathered by Red Cross volunteers in August, September and October (rank 1 being the most frequently raised theme). During the period 12 August to 21 October, 5773 suggestions were identified in the data. As presented below, the most widely cited suggestion involved expanding or modifying the vaccination programme.

Themes of suggestions identified in community feedback gathered by Red Cross volunteers, North Kivu 2018

	August	September	October
	174 responses	330 responses	1386 responses
	Beni, Mabalako	Beni, Butembo, Mabalako	Beni, Butembo, Bunia, Mabalako
Rank 1	Expand or modify vaccination programme	Expand or modify vaccination programme	Expand or modify vaccination programme
Rank 2	Other ¹	Other ²	Other ⁴
Rank 3	Community health promotion	Community health promotion ³	Community health promotion ⁵
Rank 4	Improve health care	Encourage handwashing / provide handwashing stations	Encourage handwashing / provide handwashing stations
Rank 5	Encourage handwashing / provide handwashing stations	Improve burials (particularly to allow family members to participate)	Improve health care

¹ A variety of suggestions were made ranging from blocking roads; destroying homes/latrines; examining animals; addressing transportation issues; ending the war; providing disinfectant products / protective clothing; and praying.

² A variety of suggestions were made ranging from ending the war/addressing security issues; praying; addressing transportation issues; and providing disinfectant products.

³ Most suggestions fell in to three areas: training or involving certain people more in the response; community health promotion; and distributing educational materials.

⁴ Most suggestions fell in to three areas: community health promotion; training or involving certain people more in the response; and distributing educational materials.

⁵ A variety of suggestions were made, but the majority focused on ending the war/addressing security issues; providing disinfectant products; and praying.

The following is a selection of frequently made suggestions as documented in the community feedback, clustered by key theme (not in order of frequency). A key suggestion that relates to the overall response is *'information that is provided by communities needs to be acted upon'*.

Suggestions made during community feedback gathered by the IFRC, UNICEF and Oxfam, North Kivu 2018

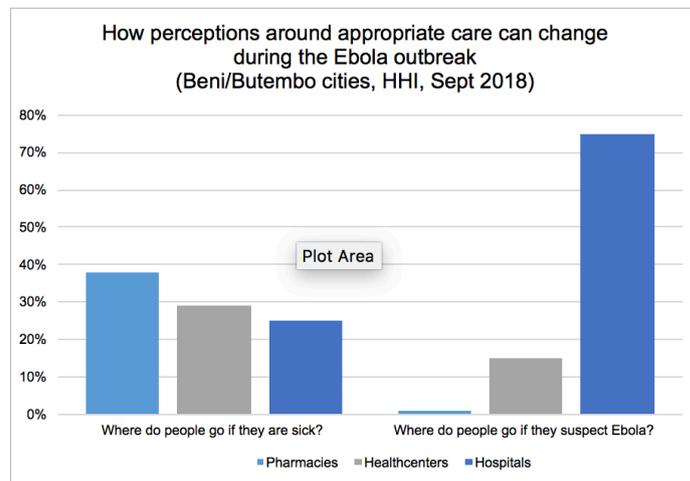
Vaccines	<ul style="list-style-type: none"> Give the vaccine to everyone without discrimination. Explain why some people are vaccinated and others are not. Involve people from the vaccination teams in community forums. They should clearly elaborate who is eligible for vaccination, who is not and why. Work more with locally respected people and/or personalities and their families, and publicly vaccinate them. It should be clear that the vaccinators should always follow the protocols and eligibility criteria and vaccinate the list constructed by the surveillance commission. Vaccination teams should be polite and show compassion. Women would like to do a pregnancy test before being vaccinated. Breastfeeding and pregnant women would like to be given the option for vaccination.
Response processes	<ul style="list-style-type: none"> Provide more details on the overall response. Raise awareness about ambulances and tell communities that an ambulance is coming before it arrives in a village. Identify 'resistant' members of the population and engage them in a dialogue. Assess the security situation in dialogue with community members. Increase the visibility of local leaders and health professionals in the response. Communicate the importance of surveillance at the community level. Explain the benefit of rapid contact tracing and transmission. Better explain the process of contract tracing and how the lists should be made. Limit the number of vehicles of the surveillance team coming into a community, and park far away from an infected house to maintain confidentiality. Brief the response teams on their behaviour: confidentiality, non-verbal attitude, being humane, keeping distance, discreetness. Use images and provide home materials for health promotion activities, in the local language of the population. Increase the involvement of <i>peuples autochtones</i> (ethnic minorities) in response activities, particularly in Safe and Dignified Burials (SDBs) in their communities. Arrive to 'decontaminate' in less than 24 hours. Make families aware of the protocol and what they should do to be safe. Apologise for and explain any delays. Inform families of any foreseeable delays in returning cremated belongings. Return the possessions the same day to help the families. Distribute soap, chlorine and buckets. Install more public handwashing points.
Diagnosis and treatment	<ul style="list-style-type: none"> Follow community specific greeting rituals and other local practices based on the advice of local liaisons. Give tours of the ETCs to overcome anxieties. Provide money for transportation so that family members or specific community groups who want to visit the ETCs can do so to visit their family members. Reduce the waiting time before entering the ETC. Please improve how people are received and admitted to diminish the feeling of abandonment; explain the reasons for the delays; create spaces for dialogue to help people wait; apologise for the delays; give visitors water; make sure food is brought on time to patients. Make family visiting hours in the morning and afternoon. Regularly contact the families of patients to give them news and to remind them that they can come and visit them. Include traditional and known healers into the ETCs to ensure community trust. Keep the emergency numbers (0999099405/0820800001) open 24 hrs a day, even at night.
Ebola vs. other diseases/problems	<ul style="list-style-type: none"> Make the Ebola results from the laboratories available more rapidly. The response needs to train other lab technicians to do the Ebola tests at the local level. Reinforce personnel to provide control at crossing points but make sure you separate them from government set up points (as these are often a source of delay and trouble for passengers). Prohibit and sanction any extortion of money to tax handwashing, and sensitise those who don't respect the handwashing rules.
Ebola outcomes	<ul style="list-style-type: none"> Engage survivors in community meetings

Burials	<ul style="list-style-type: none"> Revise the safe burial protocol with the community. Create spaces for dialogue to agree on operational procedures and quality standards. For example, use water that 'purifies' by spraying the body with chlorinated water from a distance or with a watering can; offer families the possibility of preparing their deceased relative's clothes; separate positive and negative cases in two different morgues. Explain every step of the burial intervention to the wider community. Include family members in burial practices and sensitise community members on SDB protocols, including showing body bags. Communicators need to take the time to introduce the different elements of personal protective equipment (PPE) to families. Give people the opportunity to touch clean safe PPE. Provide more funding for the Red Cross burial teams so that they can collect bodies more quickly and are able to provide more dignified care. If there are delays, inform the family about the reasons for the delay and apologise for the delays. Be patient in community dialogues to promote acceptance and mourning. In case of reluctance, redouble your dialogue, patience and compassion. Responders should not get upset [with communities]. Take the time required to dialogue with families and communities. In discussing with communities, include religious personnel. Give the floor to influential families who have lived through the SDBs and to the religious leaders who accompany the SDBs. Take a photograph of the body and give it to the family before putting the body in the body bag. Women should be involved in hygiene and infection control practices, in the decontamination of the premises, undressing and dressing the deceased, but not carrying the body.
----------------	--

Key findings

- Awareness of Ebola:** Since the start of the outbreak, Ebola-affected communities have increased awareness and basic knowledge about Ebola (risk, prevention, signs and symptoms, transmission). In UNICEF Knowledge, Attitudes and Practices (KAP) surveys (KAP-1 in August and KAP-2 in September), the proportion of total respondents in Beni and Mabalako who had been informed about Ebola increased from 76% to 98%. The majority of respondents in both these UNICEF surveys and the Harvard Humanitarian Initiative (HHI) survey (September) considered the threat of Ebola to be 'serious' or 'very serious'.
- Knowledge about Ebola:** The UNICEF KAP-1 and KAP-2 suggested that knowledge of key symptoms increased considerably between August and September (the percentage of respondents in Beni and Mabalako who could correctly name two or more Ebola symptoms increased from 47% to 95%). Such increased knowledge was confirmed in the Harvard Humanitarian Initiative (HHI) survey (September), although geographic variability was noted (with Beni city reporting higher levels of knowledge compared to Butembo). Community feedback from mid-August to November across Beni, Mabalako, Butembo and Bunia areas suggested that whilst basic knowledge about the virus increased, detailed understanding of how to prevent and respond, and why certain behaviours should be adopted, remained lower (IFRC and Oxfam). This was also reflected in the HHI survey (September) in which half (49%) of respondents in Beni and Butembo cities ranked their own knowledge of symptoms and mode of transmission as 'bad' or 'very bad', and 43% ranked themselves as 'average'. Data from the UNICEF KAPs suggested that some neighbourhoods as well as different sub-population groups (farmers, the unemployed, youth (18-25 years), people aged over 46 years and women) had less overall knowledge about Ebola and the UNICEF qualitative data gathered in Beni city in October highlighted that people were uncertain about symptoms because Ebola did not present in ways they had been told, '*it is not bloody*'. Community feedback data (IFRC: August/October/November, Beni and Bunia; Oxfam: October, Beni) also indicated that community members remained unclear about the differences between Ebola and other common illnesses with similar symptoms (including malaria, diarrhoea and typhoid). The HHI survey (September) suggested that only a small proportion of people knew Ebola could be sexually transmitted, although in the community feedback (IFRC: October/Nov, Mabalako; Oxfam: September/October, Beni), questions were raised around issues of sexual transmission and the risk of mothers transmitting Ebola through breastfeeding practices. The IFRC community feedback data from late August to mid-September in Beni, Mabalako and Butembo showed a marked decrease in the number of times witchcraft or sorcery were mentioned as a cause of Ebola, a finding corroborated by the quantitative data, but it has been reported that 'No Ebola pills' and jewellery supposed to protect against Ebola are being sold at markets.
- Prevention behaviours:** Despite the increase in basic knowledge, 45% of respondents in the HHI survey (September) suggested that they still did not know how to protect themselves or their family. The community feedback data (Oxfam: October, Beni) indicated that whilst everyone reported to have heard messaging that handwashing can prevent Ebola, very few understood why. As a community leader in Beni city stated, '*People have info on Ebola but they do not understand it*' (Oxfam data, September-October). Nearly all respondents (~90%) across the four UNICEF KAPs (conducted August to October) agreed that they had changed some aspect of their behaviour since receiving information about Ebola, but there was marked variability in the frequency of changed behaviours across different locations and populations groups, with less behaviour change reported amongst farmers and the unemployed and amongst some religious groups in Butembo. Self-reported behaviour change recorded in the HHI survey (September) indicated higher levels of behaviour change in Beni city than in Butembo city. In the UNICEF KAP-4 in Butembo area (October), reported behaviour change included: avoiding direct contact with someone who is sick with the disease (66%); frequent handwashing (57%); not touching the sick without protection (48%); not shaking hands (43%); not touching a person who died from Ebola (34%); not touching/eating dead animals found in the forest (36%); and not touching objects of a sick person (32%). According to the HHI analysis (September), higher levels of knowledge and information about Ebola are associated with increased likelihood of behaviour change. However, the extent to which reported changes in behaviour reflect actual practices remains unclear. In addition, some people reported that they were unable to adopt the prescribed preventative actions. In the IFRC community feedback data gathered in Mabalako in October-November, for example, *peuples autochtones* (people from minority ethnic groups) suggested that they were unable to follow the hygiene practices they had knowledge about because they lacked '*access to soap and handwashing facilities*'.
- Care-seeking during Ebola:** Normally, people in North Kivu will try multiple courses of action in an effort to effect a cure, and will seek different types of care either consecutively or in parallel (including biomedicine – pharmacies, health centers and hospitals –

self-medication and local healing practices). The HHI study (September) suggested that Ebola was altering care-seeking behaviour in the urban centres surveyed, particularly if they suspect themselves or a family member to have Ebola. Whilst 38% of respondents reported that they would normally seek care from pharmacies, only 1% reported they would do so if they suspected they had Ebola (a decrease from 46% to 2% in Butembo and 17% to 0% in Beni). Conversely, whilst 29% of respondents would seek care at a hospital normally, 75% reported that they would do so if they suspected they had Ebola (an increase from 31% to 84% in Butembo, and from 24% to 47% in Beni). Qualitative data collected by UNICEF in Beni city in October traced pathways of care related to sick children. Preliminary results suggested that caregivers only present children at formal health centres at a (very) late stage and having first provided home care and sought services from pharmacies, traditional healers and private trade-modern facilities. This rapid research also noted that people were reluctant to seek treatment for symptoms they attributed to other illnesses rather than Ebola. Community feedback (IFRC: August, Beni; Oxfam: September, Beni) highlighted that some community members perceived there to be an overemphasis on Ebola that was diverting attention away from other pressing health needs and stretching already limited resources. (At the time of writing, further investigations into pathways of care are being conducted). In the feedback gathered in October and November in Beni, Mabalako, Butembo and Bunia areas, some community members wanted more information about how to take care of their family members in case they were not able to present at an ETC.

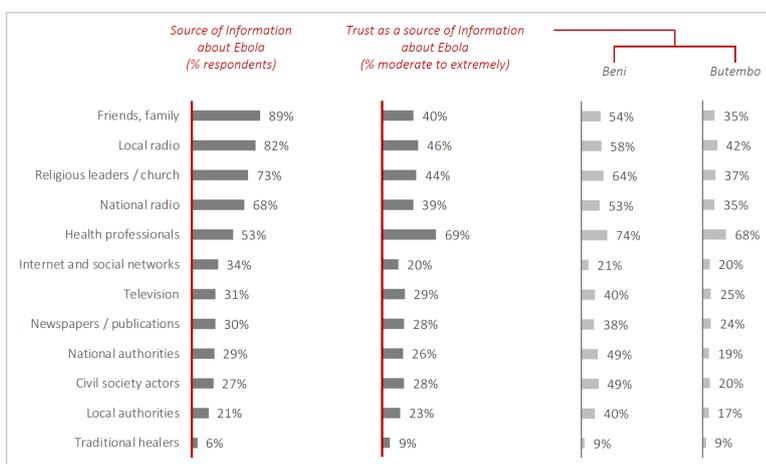


- Engagement with public health facilities:** All surveys indicated that community members had a generally positive perception of, and high level of trust in, health professionals. In the HHI survey (September), 76% of respondents across Beni and Butembo cities agreed with the statement that medical staff were preventing the spread of Ebola. Despite this, however, ongoing concerns continued to be expressed in the community feedback data. In the community feedback from Beni during October (IFRC) people highlighted their apprehension of attending health facilities, the risk of being diagnosed with Ebola (*'once you are counted as a suspected Ebola case, you cannot leave the ETC alive'*), and concerns about overall quality of care. In some cases these perceptions were influencing people to opt for self- or home-based care (as discussed above). As part of the response, free medical care is provided at all public facilities, but community members sometimes associated free care with lower quality of care and the supply of expired drugs. Perceptions that healthcare workers were being paid for sending patients to the ETCs also increased fear of false diagnosis (at the time of writing UNICEF is conducting rapid qualitative research in Beni city on the possible impact of performance-based financing on care-seeking at public health facilities). In community feedback (Oxfam: September, Beni) some people expressed concern that facilities would be closed, which would further reduce their access to healthcare, although infection prevention control also remained a concern amongst community members, particularly if *'people [patients] sick with Ebola are mixed with others'* (IFRC: August, Beni). As a result, community members consistently called for more rapid laboratory testing to confirm a diagnosis or death (IFRC: August/September/October, Beni, Bunia, Mabalako; Oxfam: October, Beni).
- Engagement with private health facilities and traditional healers:** In the community feedback (Oxfam: September/October, Beni) there were reports that the price of medicines sourced through private facilities were rising, and whilst some community members expressed reservations about private providers (associated with their financial motivations and perceptions of low quality of care and poor infection prevention control), others considered private facilities to provide higher quality care than public health facilities. An ongoing challenge for surveillance highlighted in the Oxfam report of community feedback in Beni city (October) was that community members often sought treatment from private facilities outside their immediate neighbourhood and some provided false identities. In the September-October community feedback from Beni city reported by Oxfam, Avenue Chiefs from Kasangatua and Butsili (Beni city / Ndindi), suggested that medical care was being 'driven underground' and people were seeking care from traditional healers, either in private tradi-modern clinics (that blend biomedical and traditional practices) or at home. The data sets do not specify different types of private health facilities or different types of traditional healer, and it is not clear whether care-seeking at tradi-modern clinics can be disaggregated from other types of service providers.
- Knowledge about Ebola treatment and cure:** In September, the HHI survey concluded that 67% of respondents in Beni and Butembo cities knew about the existence of treatment for Ebola. Of those who did, 82% of respondents agreed that treatment could be obtained from hospitals, and 31% from health centres. In the UNICEF KAP-1 in Beni and Mabalako in August, only 37% of respondents agreed that Ebola could be treated and cured completely. In the September UNICEF KAP-2, also in Beni and Mabalako, this had increased to 71% and in the UNICEF KAP-4 in Butembo in October, 78% of respondents agreed that Ebola could be treated and cured completely. In UNICEF KAP-4, those with higher education levels, men, health agents and teachers were more likely to agree that Ebola could be treated and cured. There were also marked variations by geographical area. In nine of the 36 villages surveyed in Butembo in October (KAP-4), less than 50% of respondents thought that Ebola could be treated or cured). In the community feedback gathered from August to November in Beni, Mabalako, Butembo and Bunia areas, community members continued to ask questions about the existence of treatment(s) and their effectiveness and availability (IFRC and Oxfam).
- Knowledge about the Ebola vaccine:** That community members were generally in favour of vaccines to prevent disease, had heard of the Ebola vaccine and were widely receptive to it, were points of convergence across the datasets. Between UNICEF KAP-1 (August) and KAP-2 (September) there was a marked increase in the number of respondents in Beni and Mabalako who reported that they had heard about the vaccine (from 23% to 91%). According to UNICEF KAP-4, 96% of respondents in Butembo in late October had heard about the vaccine (although this figure was substantially lower in two neighborhoods, 50% in Kyahali and 40% in Mitoya). The HHI survey (September) indicated that 100% of respondents in Beni and Butembo cities knew about the

vaccine (compared to the 67% who knew there was treatment for Ebola) but that only 66% of respondents agreed with the statement that they *'believe the Ebola vaccine works'*, and only 63% reported they would have accepted it if it was available to them. Of the 37% who would have refused the vaccine, 71% reported thinking it was *'dangerous'* and 23% reported their perception that it did not work (compared to 12% of the total survey respondents who thought vaccines, in general, were unsafe and 9% that vaccines did not work). These perceptions may have changed at the time of writing due to the large number of vaccinations that have now been completed (32,839 by 23 November). Yet, feedback data from August to November indicates that community members still express great confusion about the inclusion / exclusion criteria for vaccination (the strategy of ring vaccination being different to past population-wide and school-based immunisation campaigns) and continue to ask questions about its effectiveness and side effects: *'why does the virus continue to spread despite the vaccine?'*; *'why are some vaccinated and some not?'*. The UNICEF qualitative data collected with pregnant and lactating women in Beni city in October, highlighted their concern that children (who they regarded to be at high risk because *'they play in decontaminated houses'* and *'sleep in the beds of their mothers'*) were not being routinely vaccinated. Similarly, pregnant and lactating women themselves clearly articulated that they wanted to choose whether to be vaccinated or not, *'now there is no option, you just send us to death'*, *'you told us to accept [the vaccine] and now we do, but now you don't give it to save us'*. Participants in this research also discussed the perception that health workers were being given a different, more potent vaccine than the general population. The suggestion made most frequently during the community feedback gathered across Beni, Mabalako, Butembo and Bunia from August to November was to expand (or modify) the vaccination programme, *'please review your vaccine procedures'* (see below). In the October-November feedback, some community members suggested that who was vaccinated was influenced by favoritism or nepotism (*'vaccine is chosen by social class'*, *'because you know the vaccination team'*), and community respondents in Beni suggested that the response should *'make the vaccination process more democratic'*.

- Perceptions about Ebola Treatment Centres:** The UNICEF KAP-2 survey (September) found that 55% of respondents (59% in Beni, 46% in Makalako) knew that Ebola cases should be treated at an ETC, compared to 22% in KAP-1 (August). In the feedback data, it was clear that community members continued to have questions about ETCs broadly linked to concerns about diagnosis, treatment, family access and access to food. Questions about clinical outcomes increased in frequency over time (IFRC and Oxfam data, August to November, across Beni, Butembo, Mabalako and Bunia) and community members did not always understand why deaths still occurred at ETCs despite treatment being available. These issues may have contributed to negative perceptions and perpetuated misinformation about ETCs and the quality of care. Although statements such as *'they kill people in the ETCs to increase the cases'* or *'everyone that goes to the hospital dies or is accused of having Ebola'* and fears about contaminated blood and organ trafficking were still being reported in community feedback in October and November (mainly in Beni), it was not clear from the data how widespread or dominant these sentiments were or how they may have affected behaviours. Indeed, in the feedback gathered by the IFRC and Oxfam from Beni, Butembo and Mabalako in October and November, community members were reported as asking for hospitals or health facilities to be established in their area to care for Ebola patients, ideally employing local doctors and nurses trained to provide specialist care (this was initially raised in August by communities in Beni but more strongly emphasised in community feedback from the later period).
- Burial practices:** The HHI survey reported that normal burials in Beni and Butembo (i.e. not during an Ebola outbreak) typically occur one to two days after death, with the body being customarily buried by the family. Normally, there is very limited involvement or notification of administrative, religious and medical authorities. Commonly reported practices during a normal burial included publicly displaying the body prior to burial (95%), physical contact with the body (84%), and washing of the body (73%), all practices that are usually conducted by the immediate family and relatives at home. Often the body is transported to the natal home of the deceased (reported by 64% of respondents). It is unclear from the datasets how burial practices may have changed during the course of the Ebola outbreak and as a result of the introduction of Safe and Dignified Burial (SDB) protocols, although in the UNICEF KAP-2 (September), 90% of respondents in Beni and Mabalako agreed that they should not touch or wash a body to prevent the spread of Ebola (an increase from 77% of respondents in KAP-1 in August), and in October, 76% of respondents in Butembo agreed that they should not touch or wash a body (UNICEF KAP-4). There were significant variations in response by geographic location (although this was likely attributable, at least in part, to variations in community engagement activities, the timeframe of the response, communities' exposure to the outbreak, and potentially to the methodology of the surveys). The HHI survey (September) found that many of the components included in the standard SDB protocol would not normally be acceptable to respondents in Beni and Butembo cities, and in the UNICEF KAP-4 (October) only 35% of respondents in Butembo and Katwa districts believed that SDBs could be done in ways that also respected customary rites. The community feedback data (IFRC: August/September/October/November, Beni, Butembo, Mabalako and Bunia; Oxfam: October, Beni) suggested the continuation of the widespread perception that family members were not being invited to participate in the burial process, despite the strong desire and expectation to do so, and that community understandings about SDB practices remained unclear (particularly related to the use of body bags, and to diagnostic testing and the reporting of results). Although calling for community involvement, it was noted in feedback from the Red Cross in October that both men and women found it culturally inappropriate that women were involved in carrying coffins. According to the UNICEF qualitative data from Beni city (October), communities remain concerned that post-mortem Caesarian sections are not being conducted (as are customary) and that deceased pregnant women were being buried with the foetus *in utero*. In the community feedback from Bunia in October and November (IFRC) some people suggested the need for a more sensitive approach to burials (*'it seems brusque'*) whilst others in Butembo noted that significant changes had been made to ensure burials were more dignified, (*'thank you for respecting my corpse so that the burial be dignified and secure'*). Similarly, Oxfam feedback data from Beni city in October suggested that community-level confidence in the rapid response system in Kasangata had allowed burial teams to operate without facing the challenges experienced elsewhere. In the November feedback from Mabalako, community members reiterated the importance of having visual confirmation as part of SDBs to prove that their loved one was in the body bag / coffin (*'a picture of the body [should be] taken each time to assure the family that the person has been buried'*, *'or to view inside of the body bag to make sure the person is there'*). This is particularly significant given the misinformation that is circulating that body bags are filled with rocks or dirt *'so that body parts can be taken from dead bodies'*.
- Sources of information:** Across the UNICEF KAPs and HHI survey, the most commonly reported sources of information on Ebola included friends/family, local or national radio and religious leaders or church/mosque. The HHI survey (September) indicated that levels of trust in authorities, religious leaders and the media were consistently lower in Butembo city compared to Beni city. Across this survey, the most trusted source of information about Ebola was reported to be health professionals. Despite this high level of

trust, health professionals were only ranked fifth as a source of information (behind family/friends, local and national radio and religious leaders/church) suggesting that they may be being under-utilised by the response. The UNICEF KAP-3 (October) found that 94% of respondents in Beni had heard Ebola mentioned on the radio. The other UNICEF KAPs also indicated that at the community level, religious leaders were a major source of information about Ebola, and that local leaders and community meetings played a greater role in some locations (Butembo) compared to others (Beni / Mabalako) (although this variation may represent shifts in response engagement strategies over time in different areas). In the community feedback from Bunia in November, some people suggested 'take home' materials would be well appreciated (*'we need this paper to read it at home in case of problems and master the subject matter well'*). Pregnant and breastfeeding women who participated in the UNICEF qualitative study in Beni city in October highlighted the lack of specific information for mothers about how to protect themselves and their (unborn) children. They noted that whilst they often received information from community and religious leaders (in church), they rarely had the opportunity to 'meet in small circles' where they could ask questions and get answers and feedback through discussion.

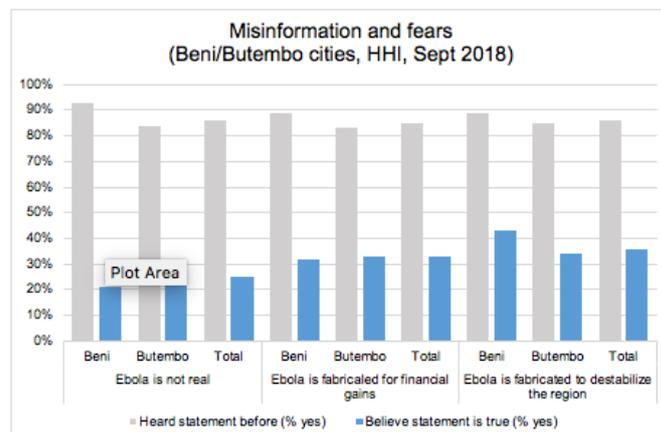


Source: Vinck P et al. (2018) Ebola Rapid Survey: Eastern Democratic Republic of the Congo, 1st survey report. Harvard Humanitarian Initiative.

- Knowledge and perceptions about the response and community involvement:** In the community feedback data reported by the IFRC from August to November in Beni, Mabalako, Bunia, Butembo, community members discussed the outbreak and response in relation to longer-term health system strengthening, highlighting persistent inequalities such as the lack of access to (clean) water, poor sanitation and weak health structures. Data from the HHI survey (September) indicated that a proportion of respondents (36%) in Beni and Butembo cities lacked information about the overall response to Ebola. In the community feedback from Ndindi neighborhood in Beni in August (IFRC) participants expressed confusion about why security barriers that were set up during the recent Cholera outbreak had not been put in place as part of the Ebola response, and in the UNICEF qualitative study in Beni city in October, caregivers asked why schools remained closed and why *'no support is provided for children'*. The HHI survey concluded that the more local an institution, the more favourably it was seen by respondents and that in general, local and city government authorities were perceived to better represent citizens' interests compared to provincial and central government. This was also reflected in the community feedback data in which people frequently asked *'why don't we see our people'* or *'our doctors'* as part of the response teams (as opposed to international or national (i.e. from Kinshasa) responders and medical staff) as this would foster greater trust and confidence in interventions. There was a strong perception expressed in the community feedback data from September to early November in Butembo, Beni and Mabalako (Oxfam and IFRC) that local leadership structures had not been systematically included in the response and that the local population remained insufficiently involved. In October, community leaders in Beni expressed frustration that they were only involved *'when problems arise'* rather than with all response actions (including where to position hand washing stations), whilst other community leaders reported feeling overloaded, *'Every organisation arrives and overflows us. The monitoring of contacts at the community level requires a lot of work'* (Oxfam). In the HHI survey (September), respondents agreed that religious leaders and churches had played a significant role in the response, but only 40% of respondents in Beni city and 31% in Butembo city stated that traditional leaders had made no contribution (which represented the least contribution of any stakeholder group). In one community feedback dialogue (facilitated by Oxfam in Beni in September), a young male participant explained that he had instigated violence against response teams because he felt that outsiders were manipulating his community (although after further consultation and support, the youth committed to raising awareness about Ebola amongst his peers). Other community leaders and volunteers who were part of the response in Beni city, expressed concern about their involvement in terms of their own security and the need for greater training and guidance (Oxfam, September). More recent community feedback data (IFRC, October-November) highlighted the perception that an increasing number of local people were involved in the response, and in paid positions, but this in turn gave rise to further questions regarding how and why people were being recruited. Concerns associated with who was being hired (*'thugs'* or *'educated people'*) were found to be increasingly frequent in the data, but accounts of positive feedback were also more frequent, *'thank you for your help, don't leave us without making everyone understand the disease'* (IFRC: October/November, Mabalako) *'the population appreciates the campaign and would like it to continue'* (IFRC: October/November, Beni).

- Insecurity and Ebola:** Frustrations regarding the ongoing insecurity in North Kivu were clearly apparent in the community feedback data. Some people question why money for Ebola cannot be spent on improving security in Beni, and others insist that stopping the massacres must be given priority before Ebola is controlled. One respondent in Bingo (Beni area) concluded, *'refusal to wash hands is a political act because nobody is dealing with the massacres'* (Oxfam data, October). Other community members question why a medical response must involve police, armed escorts and the military, and Avenue Chiefs voiced concern about the involvement of security forces leading to a rise in tensions (Oxfam data, October).

- Misinformation:** Data from the HHI survey (September) indicated that 86% of respondents in Beni and Butembo cities had heard the statement that Ebola was not real, that Ebola was



fabricated for financial gain (85%) and that Ebola was fabricated to destabilise the region (86%). Fewer respondents believed these statements to be true (25% that Ebola was not real, 33% that Ebola was fabricated for financial gain, and 36% that Ebola was fabricated to destabilise the region). Women and people from the poorest quintile were more likely to believe the statements to be true. Community feedback data also demonstrates the circulation of misinformation in Beni, Butembo and Mabalako and Bunia. Much of the misinformation should be understood in the context of North Kivu, the ongoing insecurities and power dynamics that exist as a backdrop to the outbreak and are shaping communities' perceptions of the outbreak and response. In the community feedback from August to November, statements such as 'Ebola moved here, replacing the massacres', 'Ebola is politics, it's not real', 'Ebola is not a disease, the Congolese state funds the operations in our province to prevent the elections, so they will not take place at the end of the year' and 'When the health educators ask for the names of the heads of household, it's to vote for president Joseph Kabila without knowing it' were reported. Again it was unclear how widespread or dominant such sentiments were, or how they may have affected behaviours. Similarly, misinformation about burials (e.g. the use of body bags to kill people, organ trafficking) continued to circulate (as discussed above).

- **Population movement:** The mobility of the population in North Kivu raises the risk of the spread and continued transmission of Ebola. The HHI survey reported that 78% of respondents from Beni and Butembo cities move across neighbouring *quartiers* at least once a week on average, with 43% doing so more than four times per week. Travel outside the *quartier* was less common and the frequency decreased the longer the journey: 31% reported to occasionally travel across neighboring *territoires*, with only a small proportion also reporting travel to other provinces (6%) or across the border (1%). The frequency of movement was similar for respondents from Beni and Butembo cities, and for men and women. Greater movement was associated with wealth, higher education level and occupation as a trader or civil servant. Taxi-drivers and transporters were also likely to travel more frequently and greater distances. Cross-border movement remains important along the DRC, Ugandan and Rwandan borders, with long-standing family and trade connections and due to movement of refugee populations. Feedback data from Bunia in late October highlighted concerns displaced people held about the unsanitary conditions of their camps which they perceived as a risk factor to transmission, 'the displaced (people)... wish to return to their respective villages to better protect themselves because the site has a strong concentration and risk' (IFRC).

Studies included

Data and analyses were extracted from nine studies, including five quantitative KAP surveys (collected by UNICEF and HHI), rapid qualitative data collected by UNICEF, and routine (ongoing) qualitative community feedback collected by the National Society of the Red Cross in DRC with IFRC support (and in partnership with CDC for the coding and interpretation of data) and Oxfam. Data were generated between 6 August and 6 November 2018 in various neighborhoods in Beni, Mabalako, Butembo (North Kivu province) and in Bunia (Ituri province) and were shared through the Risk Communication and Community Engagement coordination group for the Ebola response in the Democratic Republic of Congo.

Studies included in the rapid compilation of social science and behavioral data compiled for the Ebola response in North Kivu:

Organisation	Type of information	Date collected (2018)	Location	Data	Sampling comments
UNICEF	KAP survey 1	6-8 August	Beni & Mabalako areas	n=336 adults (219 Beni, 115 Mabalako)	Sampling not detailed in report
UNICEF	KAP survey 2	September	Beni & Mabalako areas	n=460 (320 Beni, 140 Mabalako)	Data available from at least 25 villages. Sampling not detailed in report
UNICEF	KAP survey (radio) 3	11-13 October	Beni city	n=400	Participants selected randomly from 30 randomly selected avenues.
UNICEF	KAP survey 4	21-23 October	Butembo area	n=475	Data available from at least 36 villages. Sampling not detailed in report
UNICEF	Qualitative data	18-29 October	Beni city	Data from focus group discussions, interviews	Purposive 'snowball' sample including women and men aged 16-50+ years, and healthcare practitioners from Ebola affected communities.
HHI	KAP survey	September	Beni & Butembo cities	N=961 (481 Beni, 480 Butembo)	Randomly selected adult respondents using a multistage cluster sampling procedure. 50% women, 50% men. Average age: 34. Results are representative for each city, with a 5% margin of error at a 95% confidence level.
IFRC and DRC Red Cross	Community feedback	21 Aug-15 October	Beni area	Compiled from 6,549 comments	Convenience sampling.
IFRC and DRC Red Cross	Community feedback	24 Aug – 19 October	Mabalako area	Compiled from 375 comments	Convenience sampling.
IFRC and DRC Red Cross	Community feedback	3 Sept – 20 October	Butembo area	Compiled from 187 comments	Convenience sampling.
IFRC and DRC Red Cross	Community feedback	20 Oct – 6 November	Beni, Butembo, Mabalako, & Bunia areas	Compiled from 4926 comments	Convenience sampling.
Oxfam	Community feedback	8 Sept – 31 October	Beni city, various neighborhoods ¹	3 reports outlining minutes and impressions from community meetings, and 2 community feedback situation reports compiled from 92 comments.	Convenience sampling including local leaders and community 'dialoguers', reflecting meetings with different population groups at community level.
Oxfam	Report	3 October	Beni city	Data from community meetings	Analysis of community feedback data, with additional insights based on field experiences and analysis from Beni.

¹ Including Ndidi, Mabolio, Ngoyo, Ngonvolio, Malepe, Bingo, Butsili, Bundji, Bella, Madradele, Mangina, Kasanga Benenguli, Linzo, Mangodoro, Mabalako and Mandima.

Methods and limitations

In general, there was a high degree of convergence in the datasets regarding key themes and issues. Where there were differences (e.g. between the UNICEF and HHI surveys), these can largely be attributed to ways in which the questions may have been asked, time period and/or geographical area. The UNICEF studies (KAP-1 and KAP-2) could be compared directly between time periods, and showed a number of positive changes in KAP indicators from August to September at the community level in Beni and Mabalako. The demographic details of respondents in the KAP surveys showed that most people were farmers or unemployed, with a smaller number of teachers, officials and other professions. In general, the studies had roughly the same number of males/females, and respondents with primary and secondary level education.

The IFRC and Oxfam community feedback was based on identifying broad trends. It is unknown whether comments were made repeatedly by the same individual, how representative the sample was or how many respondents made no comments. Overall, however, the material has been triangulated across sources. The brief also relied on various points from secondary data (including other SSHAP briefs), and included qualitative data and reporting from UNICEF and Oxfam. A number of important limitations must be acknowledged. For several of the surveys included, study design and methodologies were not available for review. The surveys often asked different questions or framed questions in slightly different ways, which made direct comparisons challenging. In most cases, we did not have access to the raw data and had to rely on power-point presentations or reports of the major findings, therefore limiting our independent analysis. Other limitations included difficulties with evaluating the representativeness of some of the data; uncertainty about how the questions were posed to participants (e.g. as open or closed questions); and a lack of clarity on how geographical location may have influenced certain findings.

Contacts

If you have a direct 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).

Key Platform liaison points:

UNICEF (kchitnis@unicef.org)
WHO (bhatiaseviap@who.int)
IFRC (ombretta.baggio@ifrc.org)
Communication Commission in DRC (idshadid@unicef.org)
GOARN Social Science Group (gobatnh@cariff.ac.uk)