Social science and behavioural data compilation (No. 3), Ebola outbreak eastern DRC February-May 2019

This rapid compilation of data analyses provides a 'stock-take' of social science and behavioural data related to the on-going outbreak of Ebola in North Kivu and Ituri provinces. Based on data gathered and analysed by organisations working in the Ebola response and in the region more broadly, it explores convergences and divergences between datasets and, when possible, differences by geographic area, demographic group, time period and other relevant variables. Data sources are listed at the end of the document. This is the third data synthesis brief produced by the Social Science in Humanitarian Action Platform (SSHAP) and focuses on data published between February and May 2019. It builds on the previous two data synthesis briefs, the first focusing on data from August-October 2018, and the second on data from November 2018 to January 2019.[1]

At the time of publication (as of 23 June 2019), 2,247 cases had been reported (2,153 confirmed and 94 probable) and 1,510 deaths (of which 1,416 confirmed and 94 probable).[2] The overall case fatality ratio (as of 16 June 2019) was 67%[3], a rise from 59% at the start of February 2019.[4] The majority of cases identified in February-May were from the health zones of Katwa, Mabalako, Mandima, Butembo, Kalunguta, Musienene and Beni.[5] There appeared to be a significant increase in the number of cases during this period due to a backlog of reporting resulting from interruptions to response activities in which teams were unable to access multiple affected communities due to security reasons.[6] Key performance indicators on response activities are routinely collected by the Ministry of Health and WHO.[7]

This brief was prepared by Kevin Bardosh (University of Washington), Ingrid Gercama and Juliet Bedford (Anthrologica), with support from SSHAP and GOARN Research Social Science Group. Feedback was also provided by colleagues from UNICEF, WHO, IFRC, the US CDC, Harvard Humanitarian Initiative (HHI), Oxfam, Translators without Borders (TwB), Interpeace and Novetta.

Community feedback: themes and questions

Multiple organisations including the IFRC and the National Society of the Red Cross in DRC, UNICEF, WHO, Oxfam, other INGOs and local partners are compiling community feedback and conducting operational research in North Kivu and Ituri provinces. According to organisations working on the ground, community feedback and research findings are analysed and discussed in Ministry of Health-led Ebola coordination structures to adjust and improve response actions. These structures include the Emergency Operations Centre, various Commissions (particularly the Communication Commission), and working groups on community feedback established in Butembo and Katwa.

The IFRC (with support from CDC) has been systematically collecting and analysing community feedback gathered from the National Society of the Red Cross since August 2018.[8] The table below presents the five themes most frequently identified in the community feedback gathered by Red Cross volunteers between February 2019 and May 2019 (rank 1 being the most frequently raised theme).[9] During the reporting period, 41,648 comments categorised as 'rumours', 'observations' or 'beliefs' were analysed. In the first months of the outbreak (Aug-Sept 2018), the majority of community feedback involved questions and concerns related to the causes of Ebola, the health system and response, and around Ebola being a scheme of the government. These issues continued to dominate feedback from November 2018 to January 2019 alongside themes associated with Ebola being a scheme of the government. In the February-May 2019 period, concerns around the quality of the health system were also emphasised. Particularly in Katwa and Butembo, many statements highlighted communities' perceptions of poor quality care and difficult interactions with response teams. These data indicate the key concerns of community members and must be taken into consideration by the response to further shape interventions, particularly in areas including Katwa and Butembo that continue to experience high levels of insecurity and threats directed towards the response and response partners.[10]

Categories of community feedback gathered by Red Cross volunteers, North Kivu and Ituri Provinces

	February	March	April	May
	12,198 codings	15, 673 codings	14,782 codings	8,268 codings
	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Lubero, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Nyriagongo, Oicha	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Musienene, Nyriagongo, Oicha
Rank 1	Ebola is a scheme of the government or others	Ebola is a scheme of the government or others	Ebola is a scheme of the government or others	Ebola is a scheme of the government or others
Rank 2	Critiques or observations of the health system	Ebola characteristics and consequences[11]	Ebola characteristics and consequences	Ebola characteristics and consequences
Rank 3	Ebola characteristics and consequences	Critiques or observations of the health system	Ebola is organised business	Ebola is organised business
Rank 4	Ebola is organised business	Ebola is organised business	Ebola is organised business	Critiques or observations of the health system
Rank 5	Ebola does not exist	Ebola does not exist	Ebola does not exist	Ebola does not exist

Questions asked by community members were also reported as part of the community feedback. During the February-May 2019 reporting period, 41,178 questions from the Red Cross community feedback were collated and analysed by the IFRC and CDC. Again, rank 1 is the most frequently raised category of questions.

Categories of questions in community feedback gathered by Red Cross volunteers, North Kivu and Ituri Provinces

	February	March	April	May
	10,673 codings	15,669 codings	15,742 codings	8,564 codings
	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Lubero, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Musienene, Nyriagongo, Oicha
Rank 1	Ebola and its consequences	Ebola and its consequences	Ebola and its consequences	Ebola and its consequences
Rank 2	Diagnosis, treatment, ETC, health system	Diagnosis, treatment, ETC, health system	Vaccine	Vaccine
Rank 3	Vaccine	Vaccine	Diagnosis, treatment, ETC, health system	Response process
Rank 4	Response process	Response process	Response process	Diagnosis, treatment, ETC, health system
Rank 5	Other questions[12]	Other questions	Other questions	Other questions

The following is a selection of questions repeatedly asked by community members between February and May 2019 as documented in the community feedback gathered by the Red Cross and Oxfam and articulated during qualitative research conducted by the *Groupe de Recherches en Sciences Sociale* (GRSS or Social Science Research Group) supported by the Ministry of Health, UNICEF and WHO. Questions are clustered by key theme, not in order of frequency.

Questions asked by community members, gathered by Red Cross volunteers and Oxfam and during qualitative research by GRSS, North Kivu and Ituri Provinces

Vaccine Questions about vaccine strategy.	Why are response teams renting very expensive vehicles yet they don't enough vaccine to give to all the community? How can a person vaccinated against this disease still get sick? Why haven't they given the vaccine to everyone to eliminate the Ebola virus? Why does the vaccination team come to vaccinate in a neighbourhood after a confirmed case? Why are they bringing a test vaccine instead of bringing one that is tried and tested?
Response processes Questions around coordination, free case, and security.	Why are the responders not collaborating with the people? Why are there several groups of outreach workers on the ground instead of coming together in a single organisation? Why don't the organisations work together? Why has the government ended the free care while Ebola is still here? Why are foreigners coming to work here while you say the disease is serious instead of letting the locals be trained in how to treat it? Can you explain why MSF left Butembo? Why are you walking around with armed police? Why take the sick by force? Who will keep the volunteers safe, they are threatened with death? Why, when there's a sick person suffering from bleeding or hernia, must the toll-free number be called? Why is it that wherever there is resistance from the population, that's where people will die in large numbers?
Diagnosis and prevention Questions about IPC measures and their functionality.	Can bleeding without other signs or symptoms also be Ebola? If someone already shows the sign of bleeding, can they have a chance of being cured? Is the use of chlorine in household water really one of the preventive measures against Ebola? Apart from handwashing, is there any other way to protect yourself against Ebola? How can we prevent this disease when we don't have water? What method can be used for hygiene without water? Why not distribute gloves to the community to better protect it? If you are married and are infected with the Ebola virus disease, should you no longer have sexual relations? If my goat has died, what should I do, since they tell us not to touch such animals?
ETC Questions about diagnosis, treatment and triage and safety procedures	How does an Ebola patient get diagnosed? Are the sick being treated and cured? Why don't people return from the ETC? Why are women dying often at the ETC? Why is it that a patient who goes to the ETC in full health, dies in 2 days? Why do people who aren't sick of Ebola die at the ECT? Why, once you arrive at the general hospital, are you driven directly to the ETC? Among ETC agents, have any died of the Ebola disease? Why are samples taken at night at the ETC? Why do the Ebola nurses leave each time with the police?
Ebola and consequences Vulnerability, spread and mortality.	Does this disease really exist? Where does this disease come from? When will the outbreak end? Why is Ebola only in the DRC but not in Rwanda? Why has Ebola just invaded the entire East of the country without attacking neighbouring provinces and neighbouring countries while our borders are not closed? Why are women often victims of the Ebola virus? Why don't the rich die from Ebola? Can a woman who suffers from Ebola give birth to a child who is already infected with the disease? Since the disease appeared, how many patients have been cured and how many have died? How long does it take to recover from this disease? Can a patient who's recovered from Ebola become infected a second time?
Transmission Inconsistency in messages, questions about pathways.	It is said that a military officer in uniform cannot catch Ebola, is this true? Does this disease come from filth? Can't dirty water infect someone with the EVD? Does Ebola live in sperm? If Ebola was real, why not forbid married couples from sleeping together? When you burn the belongings of someone who died from Ebola, can't the smoke contaminate the population? Can't you be infected by this Ebola virus disease through touching money? Here at home we eat bats, why aren't we infected? Can Ebola also be found in flour? Can the meat of a dead cow be consumed? Can't domestic animals infect us? Can the Ebola virus infect agents through mosquitoes? Ebola has the signs of malaria; why don't they give mosquito nets to the community?
Burials Questions around safe and dignified burials.	Why is the Red Cross conducting burials? Why do you wrap the victim in a plastic bag with a zipper? How long does the body bag last in the ground? When people come to bury, why are they accompanied by armed guards? Why are you burying people who died from Ebola without showing respect? Why are the responders burying those who didn't die from the Ebola virus? Why can't you give SDB training to one person in each family so that in the event of a death, they can do the burial themselves?
Other questions Questions about security, other social services and wider effects on economy/social life.	How do you explain the relationship between Ebola virus disease and the elections? Will we get to vote once the Ebola epidemic is eliminated? Why not fight the rebels who are in the forest in Beni as you fight this Ebola virus disease? What disadvantages are there to using thermoflashes? How do we go about our means of transport here in Goma (bus)? How do you explain this hassle at our checkpoints, which consists in mandatorily giving out one's identity and telephone number, is this a way of wanting to swindle us later on?

Community suggestions

Suggestions made by community members participating in engagement sessions and during regular household visits by Red Cross volunteers were also collated by the IFRC (with support from CDC). The table below presents the themes of the most frequently made suggestions during community feedback gathered by Red Cross volunteers between February and May 2019 (rank 1 being the most frequently raised theme). During the reporting period, 43,555 suggestions were identified in the data. The most frequently cited suggestion involved expanding or modifying the vaccination programme.

Categories of suggestions in community feedback gathered by Red Cross volunteers North Kivu and Ituri Provinces

	February	March	April	May
	10,307 codings	16,981 codings	16,267 codings	8,868 codings
	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Lubero, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Nyragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Nyriagongo, Oicha	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Musienene, Nyriagongo, Oicha
Rank 1	Other[13]	Other	Other	Other
Rank 2	Expand or modify vaccination programme	Expand or modify vaccination programme	Expand or modify vaccination programme	Expand or modify vaccination programme
Rank 3	Encourage handwashing	Encourage handwashing	Encourage handwashing	Encourage handwashing
Rank 4	Improve health care	Improve health care	Improve health care	Improve health care
Rank 5	Community health promotion	Community health promotion	Community health promotion	Community health promotion

The following is a selection of frequently made suggestions (clustered by key theme, not in order of frequency) as documented in the community feedback gathered by the Red Cross (with support from CDC) and by Oxfam between February and May 2019. It also includes suggestions made by participants in the qualitative research conducted by the GRSS. A key suggestion that communities continue to make relates to their perception that "*The methodology of the response agents doesn't relate with the population"* (Butembo, February 2019). This leads to frustration that "*Our requests are not solved, so it is useless every time to tell you our needs*" (Beni, February 2019) and increased hostility towards the response teams, *"Get out, response teams"* (Butembo, February 2019). Communities recommended that "*The response personnel must follow the population's views and not impose* [their own] *on the population*" (Katwa, March 2019) and "*The response team should be able to protect the population by considering their requests*" (Mabalako, May 2019). Most suggestions called for improved healthcare and the expansion of the vaccination campaign with few issues raised about burials than in the previous reporting periods. Ongoing engagement and willingness to help was also frequently reported, "*Why not declare some days as Ebola holidays to allow everyone to be involved in the response?"* (Beni, April 2019).

Suggestions made by community members, gathered by Red Cross volunteers and Oxfam and during qualitative research by GRSS, North Kivu and Ituri Provinces

Expand or modify vaccination programme	The right way to fight this epidemic is to bring us the vaccine. Distribute the vaccine to the population as you have done for meningitis, measles. The community is requesting vaccination for all, including children and pregnant women. Everyone should be vaccinated regardless of the cases that were near to confirmed cases. You need to stop the useless expenses of renting vans instead of making the money available for vaccines.
Encourage hand washing Requests for handwashing stations and water.	Give us handwashing units to put into practice hygiene measures. Give us drinking water so that we'll be able to practice proper hygiene. Try to make sure that the water supply reaches the remote corners of the city because it is difficult to wash your hands without water. We also ask the responders to reduce the wages of their workers so that handwashing stations can be bought. Change the teams that are at the checkpoints; they don't know the work related to hygiene. The response team and the awareness-raising team should have a common language in the field to avoid resistance because we as a population see a contradiction with regard to the elements learned.
Improve health care Increase laboratory capacity, involve local healthcare providers, explain treatment, reintroduce free treatment, improve decontamination procedures.	When picking up suspected or confirmed cases there is no need to line up a procession of cars for a sick person, this system must be changed. Continue treating the sick despite the resistance of the population. Psychologically prepare sick people before they are treated or examined. To help us, instead of wasting a lot of money on renting vehicles and houses, increase laboratories for the Ebola virus and test in large hospitals so we are examined and cared for by the doctors we know. Patients at the ETC should be cared for very well in order to convince the population that is resisting. You must show the population the drugs you use at the ETC. People who burn ETCs must be punished. Our native (local) doctors must be used to treat patients instead (of outsiders). It would be better if pharmacists were trained by the response agents. Free treatment should continue until the end of the EVD because the population has no money due to the war (to pay for healthcare). Please ask the opinion of the patient and the family before transferring the patient to the ETC. The response agents should do everything so that the patient and his carer go together to the ETC, like you do during the funeral, alternatively a neighbourhood leader must accompany a sick person to the ETC. Before burning the sick person's clothes or mattresses, first you need to prepare the place where you will burn those clothes, but not out in public on the avenues.
Community health promotion Requests for further localisation: training of local doctors, involvement of local leaders and appropriate communication strategies.	Increase awareness raising sessions because there is still resistance. When you do the awareness, you must involve people from each cell (pillar), don't bring us new figures who seem to be foreigners each time. The doctors who have come here must also initiate our doctors on how to examine Ebola disease; after they go back, our doctors [can] also continue treating us. Tell the response agents to study the field carefully before bringing in outreach workers. The response agents must make friends with the population to make them understand that the disease exists. Always inform the chief that an awareness campaign will be carried out in his area. Involve the Mai-Mai in awareness raising and nursing. Mass awareness-raising, namely cinema and theatre are the essential means for bringing the message of fighting Ebola to the people. We want a video that shows us all the steps of a person who is sick with the Ebola virus, not drawings on a leaflet. We ask the health promoters to also think about raising awareness on sex and sexually transmitted diseases, because the virus continues to live in the sperm despite the cure.
Improve burials Requests to further localise burials.	The number of SDB staff needs to be increased. The SDB teams must show the bodies, even if they are in the body bag, before burying them. During SDB interventions, they shouldn't come with soldiers but with local leaders. You need to leave the hearse to the community to transport the corpse from the place of mourning to the cemetery. Please always involve the family of the deceased in the burial act. We want the expats to go away and that they leave the work to local personnel – it's our people who take care of the funeral and the like anyway. There needs to be a local SDB team. The responders should be able to do a swab at the home of the deceased.

Other suggestions/requests Security, focus on wider humanitarian situation and calls for grief/memorialisation.	Evacuate the soldiers who are located at the ETC because if they continue to remain there, the problem of confrontation with the Mai-Mai will not end. Avoid taking people by force every time. Never come with police in the activities of the response. We need to abandon resistance so this disease will be quickly eradicated. We must tell members of the community again and again not to throw rocks at the response team or attack them with machetes, otherwise Ebola risks ravaging us. The heads of cells, neighbourhoods and municipalities should work together to find a solution to this Ebola outbreak and to the burning of hospitals. We ask our Congolese government to want to help us first to end this epidemic, but also the massacres and the insecurity in our city and territory of Beni. We have lost a lot of brothers and sisters we need to 'immortalise' them. The response agents must study the psychological state of the community. The government must pay the bill to any person that the intervention team transfers to the ETC even if the test turns out negative. To resolve the contradiction that exists between the awareness team and the health care team, it is necessary to organise an open debate between these two teams. The Ministry of Health should cooperate with the other Ministries.

Key findings

Awareness of Ebola: In general, awareness across the region remains high. A survey by the Harvard Humanitarian Initiative (HHI) in May 2019 found that 95% of respondents across six cities in North Kivu, South Kivu and Ituri were aware of Ebola; however only 51% reported that the Ebola epidemic was real, with higher acceptance in Beni (83%) and the lowest in d'Uvira (7%) and Bukavu (3%), emphasising the continued need for sustained engagement outside the current epicentre. It was concerning that the HHI survey also indicated that 40% of people in Butembo and 35% in Katwa did not believe the epidemic to be real. In community feedback from across all locations, there was a general perception that Ebola is dangerous and comments such as "*Ebola is a massacre*" (IFRC, Katwa, March 2019) were representative. In addition, respondents in the IFRC data from Komanda (March 2019) reported that some areas may have been 'left out' of awareness efforts and emphasised that *"Responders should not limit themselves to awareness raising in large cities, but also reach the farmers in the bush so that they can understand the danger of the EVD. Make sure you reach the more remote areas".* In the May HHI survey, nearly half of respondents in Butembo (43%) and Katwa (49%) and more than half in d'Uvira (53%) and Bukavu (64%) reported not having any information about Ebola. Although in Beni, 61% reported that the information about Ebola was sufficient, less than a quarter of respondents from Goma (22%), Bunia (22%), Butembo (18%), Katwa (14%), Bukavu (2%) and Uvira (2%) agreed with this statement. Respondents confirmed their preferred sources of information about Ebola to be hospitals (40%), family and friends (38%), radio (38%) and health centres (35%). By comparison, a KAP survey in Mandima conducted by the GRSS in April found much lower confidence in Ebola-related information distributed by health workers (7%) and greater confidence in family members (92%). Although this proportion was inverted in a similar sample from Mabalako (89% and 4% respectfully), only 29% of participants reported having actually received information from health workers.

Knowledge of Ebola: Data suggested widespread recognition across affected areas that the virus spreads from person-to-person, but the perception of it as "*a fatal disease"* without a cure persists (IFRC and Oxfam). The May HHI survey found that just over 40% of respondents from Butembo and Katwa reported that all people infected with Ebola die. In the April 2019 GRSS survey, 36% of respondents in Mandima suggested that Ebola could not be cured, compared to only 3% in Mabalako. Important knowledge gaps remained. The percentage of respondents in the GRSS survey (April 2019) who could list at least three ways to prevent Ebola was 59% in Mabalako and 41% in Mandima, and in all areas from which community feedback was reported, important knowledge on transmission, symptoms, prevention and control remained incomplete or insufficient. There were a significant number of questions asked about the origins of the outbreak, *"How can you control a disease when you do not know its origin?"*; "*What is the origin of Ebola disease in the city of Butembo?"* (Oxfam, Katwa, April 2019). In many cases, people blended a combination of fact and misinformation. Community feedback data highlighted that some respondents continued to suggest that the Ebola epidemic "*does not exist*" (Katwa, Butembo, Mabalako, Karisimbi, Komanda, Beni, Oicha, Goma, and Rwampara, IFRC January-May 2019) and 58% of respondents to the HHI survey (April-May 2019) reported this. It is a perception that appears to be decreasing over time, however.[14]

The 'special status' given to Ebola in comparison to other epidemic diseases like malaria and cholera, and the lack of haemorrhagic symptoms seen in patients and by the community, is a continued theme that contributes to the notion "*Ebola is not real*". Statements including "*The dead of Butembo do not show bleeding. It's not Ebola"* (Oxfam, Katwa, March 2019) and *"The signs of the disease are different from those on the posters, we never saw the blood poured out of the body"* (Oxfam, Beni, April 2019) are frequently collected. The association of Ebola with bleeding causes concern as related to women who vomit or bleed during pregnancy and are therefore *"Afraid to go to get care because they may be taken as a suspicious* [Ebola] *case"* (Oxfam, Beni, April 2019). A strong association was found in the community feedback data regarding Ebola infection with women, children, certain blood groups (O or O+) and "*poor people*", and some feedback attributed a degree of blame to certain population groups, *"The displaced and those who are ignorant of hygiene are the ones who are filling us with Ebola disease"* (IFRC, Mabalako, March 2019); "*Ebola is an intelligent disease that recognises who is poor, who is not a police officer, who is not an authority, etc."* (IFRC, Katwa, May 2019). In areas where the outbreak appeared to wane before new cases were reported, community members frequently blamed the movement of people as well as response teams as contributing to transmission (as reflected, for example, in Oxfam data from Beni, April 2019), and concerns were expressed that a survivor who was "*cured*" was still a risk to the community (potentially due to risks associated with sexual transmission), "*If cured people still pose a danger, why not remove them from the community as they are reservoir of Ebola disease for nearly 500 days?"* (Oxfam, Beni, February 2019). There was also a general sense that aspects of the response were an "*over reaction*" (at least in areas without active cases), and repeated calls to "*de-dramatise*" Ebola.

A study by Translators without Borders in February 2019 in Goma (the largest city in the region, which at the time of writing had not reported any cases), concluded that key concepts related to prevention and treatment were widely misunderstood due to the use of inappropriate language, particularly among women aged over 35 years and men aged over 51 years.[15] These groups also had the most difficulty interpreting Ebola risk communication material. For example, the word used on many Ebola leaflets for 'fever' in Swahili ('*homa*') actually means 'cold'. One poster that was analysed was perceived to be telling everyone who had a cold to go to the Ebola treatment centre, which caused confusion and fear. The research highlighted the need to communicate in the languages (and mix of languages) used locally, beyond just Congolese Swahili. Even in its predominantly Swahili-speaking sample, the study found that some concepts were more commonly referred to using loan words from other languages. For instance '*gencives sanglants*' ('bleeding gums') was not widely understood in French, and the word participants used for 'gums' was the Hunde term '*bihanga*'.

Knowledge of Ebola among health workers: Research by the GRSS identified important knowledge gaps amongst health workers: 76% of health workers surveyed in Mandima and 39% in Mabalako (n=76 health workers from 36 facilities, April 2019) reported that they felt insufficiently informed about Ebola, with most requesting more information on prevention, vaccination and burials. In the GRSS health worker survey in Katwa and Butembo (n=130 health workers from 65 private and public facilities, May 2019), 63% of health workers did not mention sexual transmission, and 48% did not mention touching a dead body as potential Ebola transmission routes. In Mabalako, 29% of health worker respondents and 30% in Mandima did not know there was a therapeutic treatment available for Ebola. By comparison, 95% in Katwa and 89% in Butembo of health workers surveyed the following month knew there was therapeutic treatment (with 44% in Butembo and 3% in Katwa reporting it was 'experimental'). In comparing the two surveys, it appeared that health workers in Mandima and Katwa had received less inter-personal communication training on Ebola than those in Mabalako and Butembo. In Mabalako, for example, 67% of health workers reported having received training on how to communicate with patients suspected of having Ebola; however only 17% of health workers from Mandima reported this. In Katwa, 49% of health workers respondents and 45% in Butembo reported that they did not feel capable of speaking about Ebola to patients or members of their community, and approximately the same percentage across both areas (48%) did not feel sufficiently informed to identify an Ebola case. A concerning finding from the April 2019 GRSS survey was that 100% of health workers who participated in Mandima and 77% in Mabalako reported that they would remove their PPE if asked to do so by a patient.

Prevention behaviours: To date, systematic tracking of changes in behaviours or the effectiveness of particular community engagement strategies over time has been limited.[16] HHI surveys in Beni and Butembo (September 2018, December 2018 and May 2019) provide the only consist, comparable and (at the time of writing) available longitudinal data (see table below). In Beni, there were gradual decreases across a number of indicators over time: washing hands more frequently than normal (97% to 66%); avoiding contact with those suspected to have visited an Ebola affected area (87% to 66%); and avoiding contact with the body of a person who had recently died from Ebola (93% to 78%). In contrast, certain behaviours were shown to have increased in Butembo (e.g. reducing physical interaction with others, 46% to 58%; avoiding contact with people suspected of having visited an Ebola affected area, 69% to 82%; avoiding contact with somebody with Ebola, 72% to 85%; and avoiding contact with the body of a person recently deceased from Ebola, 74% to 85%). These trends reflect the shifting epicentre of the outbreak, from Beni in September 2018 to Butembo in May 2019. In May, Novetta reported a level of 'complacency' for certain preventative measures in Beni, including lack of upkeep at sanitary (hand-washing) stations and "*Inadequate disposal methods for safety gear worn by response teams*" (Novetta, 9-16 May 2019). Communities continued to frequently ask about prevention practices, including the risk of consuming bush meat (*"We often eat the meat of wild animals, but we're not infected",* IFRC, Komanda, February 2019) and the risk of sexual contact. Some questioned why barriers preventing free movement (including quarantine) and temporary bans on public gatherings had not been introduced as in earlier cholera outbreaks (this was most frequently raised in Beni but also in Butembo and Katwa). The IFRC community feedback data repeatedly highlighted that communities struggled to follow IPC advice from response workers due to the limited availability of water in some affected areas, particularly in areas where there was a high percentage of (former) IDPs or refugee populations, "*We that live here don't have access to water – how do you want us to wash our hands?"* (IRFC, Nyiragongo, March 2019). Feedback collected by IFRC volunteers also reported discrimination against displaced communities including statements such as *"The displaced and those who are ignorant of hygiene are the ones who are filling us with Ebola disease here at home"* (IFRC, Mabalako, March 2019). The thematic brief published by CDC and IFRC in May 2019 also noted various suspicions related to contact tracing, "*You are the ones spreading the disease*" (IFRC, Beni); "*It is your livelihood*" (IFRC, Butembo) with people suggesting that response agents were "*Taking away those who are not sick"* (IFRC, Katwa).

Self-reported changes in Ebola risk behaviours in Beni and Butembo, from HHI surveys in September 2018, December 2018 and May 2019

Statement	Beni			Butembo		
	Sept 2018 n=480	Dec 2018 n=302	May 2019 n=610	Sept 2018 n=480	Dec 2018 n=300	May 2019 n=601
Wash hands more frequently	97%	80%	66%	88%	85%	82%
Reduce physical interaction with others	77%	87%	61%	46%	37%	58%
Reduce physical interaction with relatives	54%	86%	58%	22%	11%	21%
Avoid contact with people who had contact with someone infected with Ebola	82%	68%	64%	72%	45%	67%
Avoid contact with people suspected to have visited Ebola affected area	87%	87%	66%	69%	37%	82%
Avoid contact with someone who has Ebola	85%	65%	76%	72%	82%	85%
Avoid contact with the body of a person who recently died of Ebola	93%	72%	78%	74%	82%	85%

Care-seeking and home care: The similarities of early Ebola symptoms with malaria have remained a considerable challenge for early presentation. Furthermore, there were suggestions in the community feedback that Ebola was having a detrimental effect on healthcare utilisation in general. Community members raised concerns that "*All illnesses*" were reportedly being labelled as 'Ebola', "*The moment someone's sick with malaria, you say it's Ebola"* (IFRC, Butembo). This continued to fuel mistrust in the response, raised concerns about the flow of Ebola money and reinforced communities' perceptions that quality care for other conditions was being neglected. The following statement was representative, "*Today if you have a fever of 38 degrees, a procession of vehicles will arrive at your home* [whether you have Ebola or not]*"* (Oxfam, Butembo/Katwa, April 2019). GRSS research in the reporting period indicated that therapeutic routes continued to be influenced by proximity of service delivery, perceptions of illness and potential services, trust in different options and service providers, knowledge, power and influence, and associated costs. Financial barriers associated with seeking care were linked not only with transport but also out-of-pocket costs concerning food and care. Access to health facilities and ETCs was viewed through a social lens: proximity facilitated easier follow-up by families and made it more likely that patients had a degree of social connection with healthcare workers, who are known and accountable to them. Community members continued to request that isolation of suspected cases be community-based and that testing be done locally (as in previous cholera epidemics in which local nurses, Red Cross volunteers and community actors provided triage and care at *Formations Sanitaires* (FOSA) isolation units set up in schools). Community members expressed a strong preference for the response to accept and strengthen the capacity of women leaders, nurses and community agents to provide home-based support (equipped with appropriate home-care kits) (IFRC February-May; GRSS April-May 2019). The thematic brief published by CDC and IFRC in May 2019 also highlighted calls for home care, "*The population says that it is better to die at home instead of going to die at the ETC"* (IFRC, Katwa).

Engagement with public and private health facilities: Since the beginning of the outbreak community feedback has highlighted repeated requests for greater integration of Ebola-related interventions with the primary healthcare system, including a shift towards outreach activities for childhood vaccination, malnutrition and malaria. The calls for greater integration, training and engagement with local health workers coexisted alongside more negative community feedback that suggested trust in (formal) health workers had declined during the Ebola outbreak. Some community members reported avoidance of hospitals for fear of contracting Ebola at health facilities, *"Ebola virus disease exists at present in hospitals and* [they] *have become dangerous"* (IFRC, Beni and Katwa, March-April 2019). There were reports of decreased quality of care, medication shortages (particularly for the chronically ill), the need for greater infection prevention control (IPC) materials, the closures of health posts and reduced staff at facilities, *"At the general reference hospital in Beni, the sick have been abandoned. This is the reason why suspected* [Ebola] *cases have increased"* (Oxfam, April 2019). The GRSS surveys with health workers (April-May 2019) found that 100% of participants in Mandima, 74% in Mabalabo, 58% in Katwa and 41% in Butembo reported a reduction in community trust due to the Ebola epidemic. In Mandima, 100% reported accusations from the community associated with their "*Work for Ebola*", whilst 68% in Mabalako, 60% in Katwa and 55% in Butembo reported that Ebola caused conflict with their communities. These concerns were grounded in reality given the number of nosocomial infections and confirmed cases amongst health workers (121 as of 16 June 2019, including 37 deaths, accounting for 6% of cases).[17] A concerning finding from the GRSS survey of health workers in May 2019 was that 92% of health workers respondents in Katwa and 67% in Butembo did not believe their health facility had the capacity to stop Ebola transmission, which was largely attributed to a lack of (even basic) protective equipment (the reason provided by 84% of health worker respondents in Katwa and 32% in Butembo). In the IFRC community feedback data, fear of public health centres appeared most widespread in Butembo, Katwa and Komanda, particularly during the February-April 2019 period when the caseload was highest in these areas. As one community member noted, "*We're afraid to go to the hospital because every disease today has become Ebola. The other diseases have disappeared"* (IFRC, Katwa, February 2019). Community members also expressed concern that providers had "*Been corrupted by Ebola money*" (*"This disease doesn't exist. It's just a creation of white people and UNICEF to gobble up money",* Goma*,* February 2019) and may be "*Killing people*" on purpose (IFRC, Katwa, March-May 2019). Across North Kivu, care-seeking continued to rely heavily on the private system as people sought care from pharmacists and private clinics, including tradi-modern practitioners, often as their first course of action. There were reports that local private practitioners were *"Hiding the sick from the agents of the response as they take you away directly to the ETC if they find you"* (Oxfam, Katwa, February 2019). From the available data, it appeared that pharmacies had not been adequately involved in response efforts, despite their major role in healthcare provision (and potential referrals), and in some areas similar concerns were reported about the lack of involvement of traditional healers (IFRC, Beni, March 2019). In the GRSS survey in May 2019, 89% of health workers across Butembo and Katwa suggested that tradi-modern practitioners were not being involved in the response, and 32% claimed pharmacists were not included. Qualitative research by GRSS and community feedback data also suggested increased self-medication during the outbreak, *"The community prefers to buy drugs from the pharmacy instead of going to the hospital for fear of being put in the ambulance"* (IFRC, Beni, March 2019); "*We are going to look for traditional medicines to treat ourselves, because all the patients you take away with you never come back"* (IFRC, Nyiragongo, March 2019). Clearly, this has the potential to negatively impact early detection, referral and rapid treatment.

Perceptions of ETCs: The notion that '*When somebody goes to the ETC, they do not come back*' is frequently recorded in the IFRC community data (e.g. Katwa, Butembo, Oicha, Masereka, Bunia in March-May 2019) and there have been accusations that '*The ETC is a butcher's shop*", with scepticism around the use of drugs (*"The doctors inject patients with products whose origin they don't know",* IFRC, Beni, March; "*We are given injections mixed with salt* [at ETCs] *that cause death",* IFRC, Katwa, March 2019) and body bags, and fear that response partners "*steal*" a patient's blood and other body parts (e.g. Katwa and Butembo, IFRC, Oxfam, Novetta and GRSS data, February-May 2019). Concerns that continue to be expressed include: community members are not allowed to visit patients and that ETCs lack resources (staff, materials) to correctly treat and support patients, "*We heard that at the ETC there is no follow-up for the sick and that is what causes many deaths*" (Oxfam, Butembo/Katwa, April 2019), "*people go hungry"* (Novetta, Butembo, May 2019, also in IFRC data); pregnant women must now deliver only at ETCs (IFRC, May 2019); people are dying from illnesses other than Ebola at ETCs; ETCs will soon replace all hospitals; limited qualifications of ETC staff and quality of care; and perceptions that there is preferential treatment for people who are 'well-connected' (CDC IFRC thematic brief, May 2019). Data from multiple sources highlight concerns about testing, including why there are unacceptably long delays between the test and sharing of results ("*People die before receiving their results",* IFRC, Katwa, May 2019), and why rapid tests cannot be done in the community or at 'normal' health facilities (as for malaria and HIV). Contradictory first and second test results have also led to accusations about the validity of the tests and "*lying staff*" (Oxfam, Katwa, April 2019, also reflected in IFRC data). Many requests were recorded in the IFRC community feedback data for Ebola testing to happen in existing health centres so *"People know the state of their health without going to the ETC"* where they were afraid they would die (IFRC, Katwa, May 2019). Research from GRSS also highlighted concerns about health workers dressing in PPE and the colour of the PPE used (PPE was discussed in the following terms "*Dressing as ghosts coming to take the dead; When family members are given the option to dress in white PPE, this can be viewed as a bad omen;* and *"Black and red are also colours related to death, whereas (light) blue or yellow would be accepted*")[18]. Feedback also documented communities' concern and distrust that "*Soldiers guard the ETCs*" (IFRC, Katwa, April 2019), whilst local media outlets in Butembo reported that pedestrians were "*being harassed*" by soldiers on duty outside the ETC who were confiscating their money and mobile phones (Novetta, March 2019).

Knowledge and understanding about the Ebola vaccine: In the survey conducted by HHI in May 2019, an average of 79% of respondents across the survey sites had heard of the Ebola vaccine. In Beni, Butembo and Katwa, over 90% of respondents had heard of the vaccine, and 12% reported to have received it. Whilst vaccine acceptance appeared high amongst respondents in currently non-affected areas (74% of respondents in Bukavu confirmed they would accept the vaccine if offered it, 73% in Uvira, 63% in Goma and 52% in Bunia), the survey suggested that attitudes towards vaccination had deteriorated over time in areas with Ebola cases. In the HHI survey conducted in December 2018, 70% of respondents in Beni and 38% in Butembo suggested they would accept the vaccine, but in the May 2019 survey, this had reduced to 55% in Beni and 31% in Butembo. Similarly, perceptions of the effectiveness of the vaccine (that it could prevent or cure Ebola) had also decreased, from 83% to 73% in Beni and from 53% to 40% in Butembo. Since the start of the outbreak in August, confusion (and frustration) about vaccination has remained one of the most significant and frequently raised issues in the community feedback across all areas, and consistently ranked as the most important concern from February to May in the IFRC data. Requests to *"Distribute the vaccine to the population as you have done before for meningitis and measles"* (IFRC, Katwa, April) and "…*Stop renting expensive cars, instead use the money for more vaccines*" (IFRC, Butembo, March) were very common sentiments. Belief in the existence of two vaccines continued to be expressed in all locations:

one vaccine being perceived as "*real*" and given to "*the rich*", "*doctors*" and "*authorities*", whilst the other that was "fake", for the "*poor*", patients and community (IFRC/Oxfam). Communities have consistently indicated that they did not understand the selective vaccination strategy nor the eligibility criteria because details had not been communicated to the broader population. This created a vacuum of information that continues to exacerbate mistrust in the response and has widespread ramifications with people continuing to ask, *"Why are people vaccinated in secret?"* (Novetta, Beni, April). Other recent data from Katwa, Butembo and Mabalako associated vaccine hesitancy with the experimental nature of the vaccine (*"I have refused the vaccine many times. I am not a laboratory guinea pig for their vaccine to be tested on my body",* Novetta, Beni, April 2019), and fears linked to potential immediate and long-term side effects including impotence; the effect the vaccine may have on those with pre-existing health conditions; that it may kill certain blood groups (group O/O+); and that it contains posion (IFRC, February-May 2019). In other statements direct links were made between the vaccine and the transmission of Ebola, *"It is said that after five years, all people who received the vaccine will die from Ebola"* (IFRC, Katwa, March). The thematic report from CDC and IFRC published in May also recorded concerns around force being used for vaccination (*"If you refuse the vaccine, you're arrested by police elements",* IFRC*,* Rwampara) Translators without Borders tested the first page of the Swahili version of the vaccine consent form during focus group discussions in Goma in February 2019.[19] All participants had difficulty comprehending the consent form, particularly when it contained technical or unfamiliar words in French, elevated Congolese Swahili or standard Swahili (from Tanzania/Kenya). Seemingly basic words that were expressed in standard Swahili such as "*fomu" ('form')* and critical concepts such as "*ridhaa"* ('*consent'*) or "*chanjo"* ('*vaccine'*) were not well understood, particularly by women over 35 years old. The study suggested that "*ruhusa*" might be more appropriate for 'consent' and "*eneo*" for 'ring', although such terms need to be field-tested in different locations. As one female participant concluded, *"Someone needs to change these messages* [in the vaccine form] *into* [local] *Swahili so that everyone can understand."* In the IFRC community feedback data, statements such as "*Vaccinators must be able to have time to talk to concerned people"* (Butembo, May 2019) were frequent. These studies, in addition to research conducted by the GRSS in Butembo and Katwa, emphasise the urgent need to refine the risk communication and community engagement strategies and messages related to vaccination, particularly given the implementation of new protocols, and the potential introduction of a second vaccine by Johnson & Johnson.

Terminology used in the response: Findings from ongoing rapid research conducted by GRSS in Katwa and Butembo (some triangulated with data gathered by Oxfam, IFRC and Novetta), identified a number of terms regarding Ebola treatment and response strategies that had been translated from French into Congolese Swahilli but which confused community members when used in communication and materials.[20] Given the context of insecurity, military conflict and local political dynamics, such confusion may have further reinforced misinformation and suspicions. For example, making an *'*alert' was viewed as alerting the police when something was wrong (normally, you do not alert an ambulance, but rather you call a doctor). Community members associated the term with being "*being picked up*" by the security services, which was inherently negative. The word *'*positive' was seen to signify "*all is okay, all is good*"; so its use in relation to test results was counter-intuitive. In some cases, a 'positive' result was understood as being *"all clear*" (i.e. negative) and this led a number of families to refuse referral(s) to an ETC (a problem also identified in how HIV test results were conveyed in the area). The term 'Ebola case' was seen to be dehumanising, and it was suggested that 'sick' or 'ill' or 'patient' were more appropriate terms. The words *'*survivor*'* and *'*conqueror' were found to have strong associations with war and conflict: a survivor is understood to be a soldier returning from a war; a conqueror' is someone who should have died but escaped. Both terms reinforced the presumed connections between Ebola and the ongoing violence and insecurity, and the notion that Ebola was deliberately introduced to eliminate the Nande people (e.g. as a "*weapon of war*", that "*came just for one tribe"*).[21] To others, 'survivor' had spiritual associations with ghosts – in local Nande religious beliefs, 'survivors' are known to be the spirit of a dead person driven from the afterlife. In their research from May 2019, Interpeace suggested that fear of Ebola has been exacerbated by the language response teams have used to communicate with at-risk and affected communities.

Burial practices: The IFRC community feedback data from September to March showed a dramatic fall in the reporting of concerns and misinformation related to safe and dignified burials (SDBs) and local media monitoring indicated a similar decrease in the number and range of complaints about burials at major regional media with headquarters in Goma and smaller more local media including informal local radio channels (Novetta, February-May 2019). Many positive statements were captured in the IFRC and Oxfam feedback, "*Before, the responders would hide the dead bodies, but today it's good because they've just agreed to bury the dead where the family wants, thanks for that*" (IFRC, Mabalako, March 2019). With greater acknowledgment of the need for SDBs and their increasing demand, suggestions about how to improve them were also frequently documented in the community feedback, particularly related to providing training and support for communities to be involved in the preparation of a body prior to burial (IFRC, Oxfam, all sites, February-May 2019). Analysis by GRSS indicated that the preparation of a body after a death in an ETC should include at least one family member to physically view the face of the deceased or at least be provided with a photograph or video of the body (Butembo and Kwata, December 2018-February 2019). Customarily, older women are responsible for preparing a body (closing the eyes, mouth, washing the body, correcting the posture, arranging the hairstyle and dressing the body) whilst men dig the grave and transport the body (GRSS/Oxfam, February-May 2019). It has been reported that communities have refused to let a burial proceed when a hole was not made in the body bag, and the coffin was not rotated (to accommodate Nande spiritual beliefs) (GRSS/Oxfam, February-May 2019). Concerns about the burial of pregnant women with the foetus in utero also continue to be raised. Coffins were also noted to be a point of tension. It is socially important for families to buy and choose the casket as a sign of respect and whilst the provision of coffins / caskets by the response was mostly welcomed (*"I am thankful to the response team to provide us with coffins and to accompany us during the burial"*, Oxfam, Beni, February 2019) it remained unclear how extensive this practice was. Some community members have complained about the lack of cash transfer options and the low quality of coffins provided (GRSS, Butembo and Katwa, April 2019). Other concerns linked to burial practices continued to circulate and be reported in the community feedback data, often linked to the delay between notification and the SDB team's arrival ("*Whilst the body is decomposing"*), perceptions that the response is "*hunting*" for bodies, harvesting organs and burying people alive in body bags (IFRC/Oxfam, various sites, February-May). In some cases, long waiting times led to youth and political groups mobilising to block response teams from accessing sites (GRSS data and reported in WHO and UNICEF Sit Reps).

Psychosocial support: Affected communities clearly articulated the stress that the outbreak had on their daily lives, "*The problems of the disease scare us a lot because we don't think we can enjoy anything until the disease is brought under control, and we risk losing confidence in everything you say. Will the Ebola outbreak ever end*?" (IFRC, Mabalako, May 2019). Communities continued to ask for greater sensitivity to be shown by the response and expressed a high level of concern and fear ("*It's the Ebola people; don't open the door*", IFRC, Goma, February 2019) which is layered on top of the extreme stresses experienced as part of daily life in North Kivu,

particularly given the ongoing insecurity: "*If EVD returns to the areas already under control, we will be plunged into despair*" (IFRC, Mabalako, March 2019); *"The improvised security climate at the moment sinks us into fear and despair; for us God alone remains the solution and final answer to this danger that we are facing"* (IFRC, Mabalako, May 2019). Recognising this need, mental health and psychosocial support (MHPSS) services continue to be provided to communities across affected and at-risk areas (including Beni, Mabalako, Butembo, Goma, Bunia and Komanda) by locally recruited 'psychosocial agents' who offer emotional and material support to individuals and families affected by Ebola, and to survivors.[22] In their feedback, community members called for increased psychological support, particularly in relation to "*preparation*" before going to an ETC, for example through the use of short videos to showcase the ETC environment and IPC measures prior to admission (IFRC, Katwa, April 2019). Suggestions from the community included, *"Psychologically prepare sick people before they are treated or examined"* (IFRC, Katwa, March 2019), and "*Do everything so that the patient and his carer go together to the ETC. We ask that a family member be allowed to be caregiver to an Ebola victim during treatment, like you do during the funeral*" (IFRC, Butembo, February 2019). UNICEF continues to support psychosocial agents and suggested that throughout the reporting period (February-May 2019), one key operational concern was that this cadre of response workers were often notified or called too late by surveillance teams and other pillars, particularly in relation to engaging individual, families and communities before the transferring of a patient to an ETC. Stigma associated with Ebola and care at the ETCs appeared widespread and manifested in various ways. In the Oxfam feedback from Katwa (April 2019), one community member explained, '*All my neighbours hate me saying that I was corrupted by the response because after the death of my child at the ETC, I accepted decontamination, safe burials, vaccination and other things*", whilst another concluded, "*I am an Ebola winner. When I testify* [to the community], *I am told that I am a 'known' person, and that is why I am still alive"*. It was noted that people die at ETCs because of "*nervous tension*, *worry, missing their family and the lack of visits"* (IFRC, Mabalako, May 2019) and in the feedback reported to the IFRC, communities stressed that they wanted to feel patient deaths "*mattered*" to the response teams (Mangina, May 2019). Requests for more formal memorialisation of deceased loved ones were increasingly highlighted throughout the reporting period. No social science data relating specifically to survivors has been identified for analysis, although in the IFRC community feedback data, there were numerous requests for the response to share more information on survival rates and survivor experiences, "*We want to see reports with how many people get cured"* (Butembo, February-April 2019). Psychosocial agents supported by UNCEF reported that many Ebola survivors were unaware of the free follow-up medical services, incentives (e.g. reimbursement of transport, food assistance etc.) and specific psychological care they were entitled to under the National Ebola Survivors Programme.

Community perceptions of the response: In the HHI survey (April-May 2019), slightly less than a quarter of respondents in Butembo and Beni (n=1,191) reported they had had contact with humanitarians / response workers, with positive encounters being more frequently reported in Beni (90%) than Butembo (48%) and Katwa (41%). More respondents in Beni (over 60%) also reported that assistance for Ebola was being provided where it was most needed and that field staff were sufficiently informed to answer questions about Ebola; in comparison, less than a quarter of respondents from Butembo and Katwa agreed with these statements. Although the IFRC community feedback data included repeated pleas to "*End the outbreak soon*", it also captured many statements of appreciation, encouragement and gratitude for response workers and the sacrifices they were making (all sites, February-May 2019): "*You have tough hearts; you don't get discouraged"* (Katwa, March 2019), "*They are doing noble work"* (Beni, March 2019) and "*If not for your presence in the region, the population here would have been exterminated"* (Mabalako, March 2019). Indeed, appreciation for health promotion made up the single largest category of statements in the IFRC feedback data (with 11,892 statements collected from January-April 2019). Despite this, feedback data from across all areas suggested that the outbreak continued to be widely viewed as a *"money-making scheme"*, *"business" or "manufactured disease".* Criticism was particularly focused on the distribution of resources and overall ownership of the response, which was viewed as being externally driven with insufficient local involvement (IFRC and Oxfam, all locations, February-May 2019). There were frequent calls for the response to *"Stop wasting money"* on fleets of rental cars, luxury hotels and hiring staff from Kinshasa (messages on social media in April, for example, suggested that WHO and MSF only employed French and Lingala-speaking staff to "*More easily kill the local population because local doctors would take pity on their brothers",* as reported by Novetta). The most common theme in the IFRC data across all locations was that Ebola is a money-making scheme (*"Ebola is a commercialised disease…it is a scam*", Butembo, March 2019) and widespread perceptions continued that associated medical staff, politicians and others with benefiting from the response and intentionally prolonging it through acts of sabotage, inflated case numbers or deliberately spreading the virus ("*How do we know that it isn't the response agents who burned down the ETCs in Katwa to drag out its stay in Butembo like we have seen in MONUSCO's strategy*", Interpeace, Mutsanga, March 2019). Community members remained concerned about what they saw as a the lack of community engagement, *"The teams have not involved locals. Do they think that locals are not able to properly solve these problems?"*; *"Why are you talking about community involvement but bringing us people from elsewhere who do not speak our language?"* (both Oxfam, Katwa, April 2019). In addition, the CDC IFRC thematic report published in May 2019 indicated that the behaviour of some response workers may be fuelling mistrust, "*The way the responders come take a suspected Ebola patient from a family is not good"* (IFRC, Beni); "*Please ask the opinion of the patient and the family before transferring the patient to the ETC"* (IFRC, Karismibi). Research by the GRSS also suggested that initial community engagement approaches were too focused on a narrow range of local leaders, without sufficient involvement of traditional structures (from the regional chief to village level) who maintain significant authority (GRSS, Butembo and Katwa, January-March 2019. Community frustrations have been linked, in part, to the non-engagement of elders and '*sages'* (respected local leaders) in the response (e.g., in the ETC inauguration in Kirimavolo) which was interpreted by some as an insult to Nande traditions ("*What sort of project is this if the community is the beneficiary but which the managers neglect the cultural practices of the Nande which value the village's old people"*, Interpeace, Kirimavolo, March 2019). There also continued to be many requests for the response to avoid close association with the police and military, *"The responders' behaviour scares us when they come pick up a person with a lot of trucks and soldiers"* (IFRC/Oxfam, Katwa, March-April); "*We don't agree with you because you go around with the police during your operations; we've come to realise that you are crooks."* (IFRC, Mabalako, March 2019). In action-research from March 2019, Interpeace concluded that perceptions of the response as being top-down and an imposition ("*The response's communicator has adopted a style of superiority, always right and wanting to impose its beliefs without feedback options*" Katwa, March 2019) were also associated with the lack of engagement with local civil society organisations which could provide an effective link to the community and help overcome rumours and negative perceptions. Whilst response teams have engaged members of civil society, Interpeace noted that this appears to have been done largely at an individual rather than institutional level, although they confirmed a number of groups had actively supported the response including *Lutte Pour Le Changement* (LUCHA,) *Solidarite Feminie Pour la Paix et le Developpement Integral* (SOFEPADI), *Centre Pour La Promotion de Sante* (CEPROSAN), *Programme de Promotion de Soins Santé Primaires* (PPSSP) amongst others. The May KAP conducted by GRSS found that 53% of health workers surveyed across Butembo and Katwa attributed the persistence of the outbreak to a lack of community engagement.

Population movement: Mobility of communities in North Kivu, South Kivu and Ituri continue to be a major risk factor for cross-border spread of the virus and continued spread to other neighbouring health zones within DRC. The HHI survey (May 2019) found that 40% of respondents in Goma and Uvira reported travelling at least occasionally to neighbouring countries. Travel to other *territoires* and provinces was highest among respondents from Goma and Bukavu. As highlighted above, community feedback reported statements of suspicion and fear associating the free movement of people with disease transmission, and questioned control measures that were in place, "*Why are the barriers open for everyone without control?"*; *"Taking people's temperature at the various checkpoints is useless… there's a flaw in the monitoring of the response teams"*; *""Why not put barriers in the villages where there are Ebola victims?"* (IFRC, Mabalako, May 2019). The first Ebola victims in Bwera, western Uganda, were a Ugandan family that had visited DRC and returned home on an unguarded cross-border footpath, highlighting the frequent cross-border movements of people from neighbouring countries.

Violence and insecurity: Community feedback data shows ongoing threats of violence against the Ebola response, with levels of hostility escalating across all health zones in April 2019, directly following the March legislative elections[23]: "*In the Vuhovi Health Zone, seven response agents have already been identified among the medical personnel who will be killed one by one"* (IFRC, Katwa, IFRC, March 2019); "*After the response, those who work* [with it] *will be kidnapped, massacred, and their homes burned"* (IFRC, Katwa March 2019). In the GRSS surveys with health workers (April and May 2019), 23% of respondents from Mabalako and 37% from Mandima reported having experienced threats to their health facilities due to Ebola, whilst 59% of health workers in Butembo and 53% in Katwa reported feeling at risk from attack. In the feedback data, some community members explained that they refused to join the response due to intimidation, *"I missed the work because I am afraid of being beaten; I am told that I will be wanted after the response* [if I participate]*"* (Oxfam, Katwa, April 2019); "*I do not want to be a member of the response because the others will think that I receive money from their blood"* (Oxfam, Katwa, April 2019). Women traders who were engaged as part of the action-research conducted by Interpeace (Katwa, March 2019) expressed concerns about the location of the ETC, noting that run-off water from the ETC polluted the river in which they washed clothes, bathed and children played. In this context, one participant expressed thanks to those who had burnt down the ETC as she felt local authorities and response partners had not listen to their concerns that the "*The ETC is a danger to the whole community*". However, community feedback also documented positive comments and requests to quickly rebuild the burnt ETCs in Butembo and Katwa, "*For MSF to return to Katwa"*, and for "*All those who fight the response teams to be hunted down and brought to justice"* (IFRC, April 2019). Explanations on social media about who has been responsible for these attacks were varied and attributed the on-going violence to sitting President Felix Tshisekedi, local Mai-Mai groups, local politicians and ex-ETC staff members amongst others (Novetta, April 2019, see also SSHAP brief, 'Politics, fractions and violence: listening to local voices on Ebola', based on material from February-April 2019).[24] Communities continued to question the positive bias that is afforded Ebola (with the corresponding influx of money, resources and personnel), and were frustrated by the lack of international strength to end the violence, "*Why are people who die by Ebola buried with honour, while people who die by knives and guns are buried in a mass grave?"* (Oxfam, Beni, March 2019).

Contact

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).

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The Social Science in Humanitarian Action: A Communication for Development Platform is a partnership between the Institute of Development Studies (IDS), Anthrologica and UNICEF. Funding to support the Platform's response to Ebola in the DRC and neighbouring high priority countries has been provided by the Wellcome Trust and DFID.

Studies included in the synthesis brief

Organisations	Study description	Timeframe of data collection	Methods
GRSS (MOH, UNICEF, WHO et al.)	Qualitative research on community and health worker perceptions	Jan 2019	13 focus group discussions and 77 key informant interviews in Butembo and Katwa. Visits to seven FOSAs.
GRSS (MOH, UNICEF, WHO et al.)	Scoping study on possible impact of Ebola (and the response) on health utilisation for maternal and child health services	Jan 2019	Mixed methods study across all health zones in Katwa. Five focus group discussions with 46 participants in five FOSAs.
GRSS (MOH, UNICEF, WHO et al.)	Qualitative data on vaccination acceptability for pregnant/breast-feeding women and young kids	Feb 2019	Qualitative study in Butembo and Katwa. 15 focus group discussions and 15 key informant interviews with 127 community members and health workers.
GRSS (MOH, UNICEF, WHO et al.)	Integration of Ebola in health services and promotion, including a focus on understanding therapeutic itineraries	Feb - May, 2019	39 focus group discussions and 156 key informant interviews in Butembo and Katwa health zones.
GRSS (MOH, UNICEF, WHO et al.)	Survey questionnaire	April 2019	Survey of 76 health workers across 19 health zones in Mabalako and Mandima.
GRSS (MOH, UNICEF, WHO et al.)	Survey questionnaire	May 2019	Survey with 130 health workers across 21 health zones in Katwa and Butembo.
HHI	Large-scale survey	April - May 2019	Random sample of adults: Goma (451), Beni (610), Butembo (581), Katwa (216), Bukavu (307), Uvira town (301), Bunia (696).
IFRC	Online community feedback dashboard containing qualitative perception data.	Feb - May 2019	A total of 41,648 community feedback comments, 41,178 questions and 43,555 suggestions. For further information about the system and methodology see: https://odihpn.org/magazine/bringing-community-perspectives-decision-makingebola-response-democratic-republic-congo/
IFRC	Thematic summary report: '*Refusals and reluctance towards: contact tracing and monitoring; Ebola treatment Centres; and Ebola vaccination*'	Jan - April 2019.	47,156 statements and 165,093 codings of community data collected by National Red Cross volunteers.
Interpeace	Actor mapping research on Ebola response resistance	Feb - April 2019	20 focus group discusisons with 415 participants and 60 individual interviews in Butembo, Beni town and Beni's territory.
Novetta	PALM Social Analytics	Feb - May 2019	Three surveys with randomly selected participants: Beni (n=100) Butembo/Katwa (n=100) Mangina (n=50). Monitored traditional media sample registered 20,000 quotes and 3,500 open source articles, radio transcripts, and press releases. Social media monitoring covered 1,500 WhatsApp users, 25 community pages, and approximately 3000 tweets per month.
Oxfam	Community feedback collected during community meetings, mass sensitisation, briefings, radio, door to door sensitisation.	Feb - May 2019	692 community feedback statements, from Katwa, Beni, Mandima and Mabalako.
Translators without Borders	Qualitative research on language and information needs of communities, focused on Goma. This included analysis of spoken, written and pictorial Ebola risk communication material (posters, brochures, vaccine consent forms).	Feb 2019	Survey with 216 participants and six focus group discussions with 75 people. Participants were adults, with different gender, age, ethnicity, geographical location (based on a quota approach).
UNICEF	Routine qualitative PSS feedback data	Ongoing	Collected during field visits from 814 locally recruited psychosocial agents.

References and notes

[1] SSHAP (2019). "Social science and behavioural data compilation, DRC Ebola outbreak, November 2018-February 2019". https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14389/SSHAP_data_compiliation_brief_2_March_2019.pdf?sequence=1&isAllowed=y
SSHAP (2018). "Social science and behavioural data compilation – November 2018". https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14144/SSHAP_data_compilation_brief_November_2018_updated.pdf
[2] https://www.who.int/ebola/situation-reports/drc-2018/en/
[3] WHO, External Situation Report 46, 18 June 2019. https://apps.who.int/iris/bitstream/handle/10665/325405/SITREP_EVD_DRC_20190618-eng.pdf?ua=1
[4] WHO External Situation Report 27 - 5 Feb, https://apps.who.int/iris/bitstream/handle/10665/279992/SITREP_EVD_DRC_20190205-eng.pdf?ua=1
[5] WHO External Situation Report 27 - 5 Feb, https://apps.who.int/iris/bitstream/handle/10665/279992/SITREP_EVD_DRC_20190205-eng.pdf?ua=1
[6] On 19 April, an attack by armed militia resulted in the tragic death of Dr Richard Mouzoko Kiboung, a WHO epidemiologist, and the injury of two other healthcare workers. Following the attack, Ebola response activities were temporarily suspended in some high-risk health areas. In Butembo and Katwa, the response was reduced to a "stop and go" pattern following a civil demonstration by members of a local moto-taxi drivers union. As a result, vaccination sites in Butembo, Katwa, Kalunguta, Vuhovi, Lubero and Masereka health zones were inaccessible for five consecutive days. In a separate event, on 3 May 2019, a safe and dignified burial (SDB) team in Katwa was also attacked after conducting a SDB of a confirmed case.
[7] The Ministry of Health and the World Health Organization have set up a tracker mapping out the various response activities available in the affected areas. The tracker for May can be accessed from https://reliefweb.int/sites/reliefweb.int/files/resources/activites_s21.pdf
[8] Further information about the system and methodology can be accessed at https://odihpn.org/magazine/bringing-community-perspectives-decision-makingebola-response-democratic-republic-congo/
[9] All ranks are based on frequency and were provided by CDC and IFRC.
[10] SSHAP (2019). "Politics, fractions and violence: listening to local voices on Ebola. Local media update #3 (February-April 2019). https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14497/SSHAP_Local_and_social_media_brief_3%20_February_April_2019.pdf?sequence=1&isAllowed=y
[11] The category 'Ebola characteristics and consequences' includes statements about characteristics of the EVD outbreak, such as its duration, severity or seriousness, person, place, time. It also includes speculation about who is affected; statements acknowledging that Ebola exists and that it's real, that people believe in Ebola; statements about the impacts/outcomes of the EVD outbreak on individuals (survival or death) and communities (poverty, families, orphans); concerns about whether Ebola exists and about the Ebola virus and includes characteristics of the disease, its symptoms, and the person's notions about what Ebola is and what they believe Ebola to be.
[12] There were 668 'other' comments reported in February, 702 in March, 655 in April and 202 in May 2019. 'Other' is a very heterogeneous group of comments that do not fit any of the codes in the current codebook being used by CDC to analyse the data. Comments in the 'other' category are regularly reviewed to identify new codes, although given the high workload, re-coding earlier data with new codes has not yet been possible. In February-May 2019, statements coded as 'other' included questions indicating suspicion with response measures ("*Are we going to abandon our relatives?", "Why can't you manage to put an end to this disease", "Why don't you tell the truth?"*), transport and travel related queries ("*How do we go about our means of transport here in Goma (bus)?*", but also: *"during the cholera epidemic, barriers were erected, why not for Ebola? Why don't you block the entry and exit of people so this disease couldn't spread to other places?"*) and bush meat related concerns ("*Are all meats sold in the butcher shops healthy?";* and: "*when the end of Ebola is proclaimed, will bats be edible?*").
[13] There were 655 'Other' suggestions made in February, 1,007 in March, 1,032 in April, and 467 in May 2019. Between February-May 2019, suggestions coded in the 'other' category included requests that the government should increase social services outside of the Ebola response; provide disinfectant products; improve decontamination procedures at the community level; improve coordination between response teams; increase social services; and block roads to put an end to the Ebola outbreak. There were a significant number of comments that appealed for increased security measures to guarantee safety and the end of war whilst "*Demilitarising the armed forces at the ETC response sites"* as "*They are the ones who cause the resistance to grow because health is not dependent on the Ministry of Defence*". There were calls for prayers to end Ebola and people also expressed the need for other materials, items or services to help flight Ebola including protective clothing and remuneration for burnt items during decontamination, and the examination of animals to ensure they were healthy.
[14] SSHAP (2019). "Politics, fractions and violence: listening to local voices on Ebola. Local media update #3 (February-April 2019). https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14497/SSHAP_Local_and_social_media_brief_3%20_February_April_2019.pdf?sequence=1&isAllowed=y
[15] Translators without Borders (2019). "Missing the mark? People in eastern DRC need information on Ebola in a language they understand". https://translatorswithoutborders.org/missing-the-mark-people-in-eastern-drc-need-information-on-ebola-in-a-language-they-understand/
[16] There is a current lack of longitudinal survey data across the region. Different data sets measure different indicators and often questions have not been asked in the same form making comparisons challenging. It is understood that measures are being taken to overcome this.
[17] WHO, External Situation Report 46, 18 June 2019. https://apps.who.int/iris/bitstream/handle/10665/325405/SITREP_EVD_DRC_20190618-eng.pdf?ua=1
[18] UNICEF External Situation Report – 28 April 2019. https://www.unicef.org/appeals/files/UNICEF_DRC_Ebola_Humanitarian_Situation_Report_28_April_2019.pdf
[19] Translators without Borders (2019). "Missing the mark? People in eastern DRC need information on Ebola in a language they understand". https://translatorswithoutborders.org/missing-the-mark-people-in-eastern-drc-need-information-on-ebola-in-a-language-they-understand/
[20] Groupe de Recherche en Sciences Sociales (2019). "*Briefing Note: Perceptions des mots et langage de la riposte*."
[21] SSHAP (2019). "Politics, fractions and violence: listening to local voices on Ebola. Local media update #3 (February-April 2019). https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14497/SSHAP_Local_and_social_media_brief_3%20_February_April_2019.pdf?sequence=1&isAllowed=y
[22] Ministry of Health and the World Health Organisation (2019): "*RD Congo - Ituri et Nord-Kivu : Suivi des activités des commissions engagées dans la riposte contre la Maladie à Virus Ebola (Semaine 21 : du 20 au 26 mai 2019*)" https://reliefweb.int/sites/reliefweb.int/files/resources/activites_s21.pdf.
[23] SSHAP (2019). "Politics, fractions and violence: listening to local voices on Ebola. Local media update #3 (February-April 2019). https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14497/SSHAP_Local_and_social_media_brief_3%20_February_April_2019.pdf?sequence=1&isAllowed=y
[24] SSHAP (2019). "Politics, fractions and violence: listening to local voices on Ebola. Local media update #3 (February-April 2019). https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14497/SSHAP_Local_and_social_media_brief_3%20_February_April_2019.pdf?sequence=1&isAllowed=y