Social science and behavioural data compilation (#5), Ebola outbreak eastern DRC, September-November 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, South 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 fifth data synthesis brief produced by the Social Science in Humanitarian Action Platform (SSHAP) and focuses on data published between September and November 2019. It builds on the previous four data synthesis briefs, (#1: August to October 2018; #2: November 2018 to January 2019; #3: February to May 2019; #4: June to August 2019).[1]

This brief was prepared by Kevin Bardosh (University of Washington), Theresa Jones and Olivia Tulloch (Anthrologica), with support from SSHAP and GOARN-R Social Science Group. Feedback was also provided by colleagues from UNICEF, WHO, IFRC, the US CDC, Translators without Borders (TWB), Novetta, World Vision/Catholic University of Bukavu and Search for Common Ground. Key performance indicators on response activities are collected by the Ministry of Health and WHO.[2]

Community feedback: themes, questions and suggestions

Multiple organisations including the IFRC and the National Society of the Red Cross in DRC, UNICEF, WHO, Oxfam, other INGOs and local partners continue to compile community feedback in North Kivu and Ituri provinces. A new initiative is bringing partners involved in collecting community feedback together with the U-Report youth engagement platform to strengthen coordination and generate action and change within the response based on community input.[3]

Between September and November 2019, data were captured through the IFRC community feedback mechanism through over 850 volunteers.[4] 36,698 points of community feedback were categorised as rumours, observations or beliefs, the most common category related to characteristics and consequences of Ebola. Themes relating to Ebola being a scheme of the government or others, vaccine suspicions and non-acceptance, and concerns about the quality of the health system continued to dominate. The table below presents the five themes most frequently identified (rank 1 being the most frequently raised theme).[5]

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

	September 2019	October 2019	November 2019
	11,269 codings	13,335 codings	12,094 codings
	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, and Oicha,	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha
Rank 1	Ebola characteristics and consequences	Ebola characteristics and consequences	Ebola characteristics and consequences
Rank 2	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 3	Ebola is organised business	Ebola is organised business	Ebola is organised business
Rank 4	Critiques or observations of the health system	Critiques or observations of the response	Vaccine suspicions and non-acceptance
Rank 5	Critiques or observations of the response	Vaccine suspicions and non-acceptance	Critiques or observations of the response

Analysis of data points categorised as "Ebola characteristics and consequences" show an increase in statements about the outbreak ending or a decline in Ebola case numbers. Questions about whether response activities would continue if the outbreak ended and requests for continued response activities increased. Questions around why response activities were continuing despite the declining case numbers were noted and suspicions about response workers reduced. Statements about the outbreak ending were highest in "cold" zones (Goma, Karisimbi, Nyiragongo, Bunia) and lowest in "hot" zones (Mabalako (Bingo only), Mambasa, Mandima (Biakato Mines only), Oicha, Kalunguta).[6]

The following table illustrates themes repeatedly captured through the IFRC community feedback mechanism between September and November 2019 clustered by theme, not in order of frequency.

Rumours, observations and beliefs community members, gathered by Red Cross volunteers

Ebola characteristics and consequences	Ebola doesn't exist anymore. The community hasn't experienced Ebola disease. Ebola exists. The population knows that the disease exists but the response workers who hire people do not have the capacity to treat patients, that is why the population is resisting. Ebola is a contagious disease. The community is satisfied because it is nearing the end of the epidemic. Some people say that the disease is coming to an end, but the population is afraid of people working in the response as they are trying the disease. Ebola came for us poor people.
Ebola is a scheme of the government or others	Ebola is a politicised disease. Ebola is a political strategy / policy of the Congolese government. Ebola is a disease made up or created by white people to eliminate Africans.
Ebola is organised business	You don't want Ebola to end because you earn a lot of money from this disease. Ebola is a government business. Ebola is a business for foreigners. It's a commercial disease created so that the government can seek financial aid.

Critiques or observations of health system	We are afraid to go to the hospital because when we take a patient directly to the ETC they are isolated from their family members. Lately nurses are not caring for the sick. Doctors abandon patients without caring for the sick. Doctors do not treat properly. We are afraid to take our patients to the hospital because they say you are injecting them with Ebola. People die at home, because they are afraid to go to hospital in order not to be contaminated.
Critiques or observations of the response	The Ebola message was badly spread by the first response team, that's why this disease spread. The rescuers are also complicit in the Ebola issue. Your thermo-flash does not give a good, accurate temperature. You create lies so people die of this disease. At the customs post the bosses don't get out of their cars to wash their hands. It is the Red Cross that gives the disease during their outreach operation. Chlorinated water will create real Ebola.
Vaccine suspicions and non-acceptance	The vaccine is deadly. Your measles vaccine is not against measles, it's against Ebola, it's a policy. Resistance is created by the response people when they said that those who have a chronic illness, pregnant women and children younger than 5 years of age must not be vaccinated, but today your vaccine is becoming mandatory everywhere. The disease continues because the response team cannot manage to implement the vaccine in all health centres. The vaccine is poisoned. The vaccine kills. Five years from now all people who have been vaccinated will die. Your vaccines cause miscarriage. Your Ebola vaccine is not effective against Ebola.

During this reporting period, 32,242 questions captured through the IFRC community feedback mechanism were reported, collated and analysed. The tables below present the themes of the most frequently asked questions (rank 1 being the most frequently raised theme) and the types of questions repeatedly captured (clustered by key theme, not in order of frequency). Questions about Ebola and its consequences remain the most common, however in this period such questions were distinctly concerned with "*When will Ebola end?*"

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

	September 2019	**October 2019**	**November 2019**
	9,247 codings	12,082 codings	10,913 codings
	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha
Rank 1	Ebola and its consequences	Ebola and its consequences	Ebola and its consequences
Rank 2	Response processes	Response processes	Vaccine
Rank 3	Diagnosis, treatment, ETC, health system	Vaccine	Response processes
Rank 4	Other questions[7]	Diagnosis, treatment, ETC, health system	Diagnosis, treatment, ETC, health system
Rank 5	Vaccine	Other questions[8]	Other questions[9]

Questions asked by community members, gathered by Red Cross volunteers

Ebola and consequences Vulnerability, spread and mortality.	When will Ebola end? Since the beginning of the EVD response how many cases have there been? Does Ebola exist? Why doesn't Ebola kill animals? What can be done to eradicate EVD? Where does this disease come from? Why does Ebola last longer in men than women? Why has this disease lasted many days?
Response processes Questions around response actions, coordination and security.	Why do you continue to raise awareness when it has been declared that Ebola is over? Why don't the response workers work at night? Does the Ebola from Mambasa sleep at night because you do not work at night at the gate? How can we put an end to this disease? Why are the hospitals guarded by armed men? Is Ebola going to continue into 2020? Instead of spending money to power television and others, can't you distribute to the people?
Diagnosis, treatment and prevention Treatment pathways and processes, IPC measures.	Is Ebola curable? Why are patients who leave for hospitals directly transferred to the ETC? Why, when there were foreign doctors at the ETC were there many deaths? Why doesn't the lab result come out soon before the burial? How can someone infected with Ebola be examined? What can we do if we get sick and cant afford to go to the hospital?
Vaccine Questions about vaccine strategy.	Why aren't you vaccinating the entire population? Why are you vaccinating us? You people in the Red Cross are you sure about this vaccine? Why do you only give food to vaccinated contacts? Are you reproaching yourself for not having posted notices for when you perform the vaccination? Is Rwanda prioritised to be vaccinated? How can we believe in the Ebola vaccine when you don't bring us the vaccine of other diseases?

The following table presents the most frequent themes of community members' requests and suggestions captured through the IFRC community feedback (rank 1 being the most frequently raised theme). A total of 31,011 comments were categorised as requests or suggestions. The most frequently cited suggestions related to handwashing and the need for other materials. This differs to previous reporting periods (February-May, June-August) where the most frequent suggestion was to expand the vaccination programme.

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

	September 2019	**October 2019**	**November 2019**
	9,999 codings	11,539 codings	9,473 codings
	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara	Beni, Bunia, Butembo, Goma, Kalunguta, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha
Rank 1	Encourage handwashing	Need for other materials	Need for other materials
Rank 2	Need for other materials	Encourage handwashing	Encourage handwashing
Rank 3	Expand or modify vaccination programme	Expand or modify vaccination programme	Expand or modify vaccination programme
Rank 4	Improve health care	Response process suggestions	Response process suggestions
Rank 5	Response process suggestions	Improve health care	Improve health care

The table below is a selection of frequently made suggestions (clustered by key theme, not in order of frequency) during this period. Whereas in the last period, the 'other materials' were more obviously Ebola-related protective equipment, in this period the 'other materials' were focused more on clean water and hygiene materials, suggesting the focus is moving away from Ebola-related needs. As for previous periods, there were fewer questions and suggestions about burials in the feedback during this period, continuing a downward trend in the data since late 2018.

Suggestions made by community members, gathered by Red Cross volunteers

Encourage hand washing Requests for handwashing stations and water.	We are asking for handwashing basins in all public places and even in each household. We need a bathroom sink. Increase the number of handwashing stations in public places. We need soap. Give us handwashing stations. Hand out washbasins, disinfectant and soap to practice good hygiene.
Need for other materials Requests for water, gloves, boots, chlorine and other protective equipment.	We need disinfectants. Distribute water everywhere. Bring us tarps to build underground wells. Give us drinking water. We need drinking water. Ask REGIDESO to send us clean water for better prevention. Give us chlorine. Increase the number of standpipes in remote areas to reduce the spread of EVD. We suggest to our brother the Red Cross to help us with WC construction in our schools.
Expand or modify vaccination programme	Please vaccinate the entire population. Immunise us. Give the vaccine to everyone, even children. We need vaccines brought door-to-door. Vaccinating the entire population would be one way to eradicate Ebola.
Improve health care ETC placement and closure, effective treatments, free healthcare.	Provide free care during the period of the epidemic. Separate the ETC from the general hospital. Look for the drug to finish the epidemic in the sperm of the cured. We suggest increasing SDB staff to cover our Komanda health zones well. That doctors treat patients without asking for money. We recommend better care for patients during the period of the response in order to quickly eradicate this disease. Please give us medicines for care. We recommend that patients be truly cared for during this period of the response to ensure that suspicious cases are properly detected in affected and untouched areas. We're suggesting good care for sick at the ETC of Komanda because you have a lot of negligence when receiving people. To the response officers: have a healing heart not to get rich.
Response process suggestions	We suggest the government puts an end to this disease or to put a checkpoint between the two provinces. We ask the Congolese government to be responsible for ending this disease quickly. We are asking for the assistance of our government when there is a death in the community. We suggest new strategies to end this disease. We ask the response teams to do everything to eliminate Ebola, we have lost a lot and suffered and we don't want to continue to live like this. We request the response teams at this check point to talk to those who do not wash their hands. We must do all within our means to close [points of control] because when the disease ends visitors will still bring it.

Key findings

Awareness of Ebola:

According to social media analysis by Novetta (September-November 2019) the volume of Ebola-related content in social and traditional media channels declined as cases have reduced, and has been replaced by justifiable concerns about governance and security challenges. The Cellule Analyse Science Sociale (CASS) under the Strategic Commission of Ministry of Health and including UNICEF, WHO, CDC, Translators Without Borders and IFRC conducted surveys in Butembo/Katwa/Kalunguta, Mambasa and Goma on preferred sources of information about Ebola; the data showed that radio continued to be the most widely used and preferred channel, although communities also valued doctors/nurses, religious leaders, posters and other channels. In Beni, qualitative research by Search for Common Ground (SCG) found that radio was perceived as reliable because it allowed validation by health authorities whereas word of mouth information was seen as less reliable. Although a patchwork of local radio stations exist around Goma, no one station seemed particularly favoured; however radio preferences in Mambasa were more clearly defined with 83% preferring Radio Amkeni (CASS).[10] Qualitative research by TWB in Beni (September 2019)[11] found that the daily radio bulletin "Koma Ebola" was well-known, although it is mostly listened to by men. Although communities may express a preference for radio, this did not mean that they necessarily considered the information to be highly trustworthy; asked about their confidence in information related to child health, all respondents in a Goma survey (CASS, August 2019) trusted community leaders whereas 44% trusted doctors, 23% nurses and only 5% radio. A Beni male focus group participant in the TWB study explained: *"Messages on the radio are a little difficult, because you don't know who is on the radio: they could be being used. For example, sometimes you hear that someone has been cured at the ETC. People say these are soldiers' wives who are paid to give testimony as Ebola survivors. But when it's word-of-mouth, you see the person. On the radio you only hear without seeing."* Qualitative research by TWB found that women (primarily responsible for household healthcare seeking) in particular preferred to receive information by word-of-mouth, although younger women with smartphones regularly listened to the radio; women also seemed to have fewer channels of information than men and were more likely to believe misinformation about the epidemic.

Social media monitoring by Novetta found that religious and local government officials in Butembo/Katwa were the primary source of Ebola awareness raising from late October 2019 as citizen narratives shifted to focus on post-outbreak scenarios. Social ties through local organisations are strong across North Kivu and there were continued calls for more direct dissemination of information by community meetings, engagement with community leaders, door-to-door sensitisation and the use of local megaphone announcements in the early morning. According to qualitative research in September 2019 by World Vision and TWB; for example, *"Talking to people is very important. You can bring billboards, you can write on them, but if people don't understand, they will not know how to ask questions. The important thing is to talk to people face-to-face, explain to them what they see on the poster. It's about talking with people and interacting with them"* (Doctor, Beni; TWB) and *"we see the posters, but often the health workers do not explain them to us, unless you ask: what does this image mean?"* (Female resident, Beni; TWB). The use of printed materials, like posters and banners, was quite rare and concentrated in health facilities, according to the TWB study in Beni (September 2019), which also found that existing material was run-down, lacked detail, was confusing, and that pictorial material was not self-explanatory. Focus group participants greatly approved of a new series of Ministry of Health/UNICEF leaflets, but they also asked for one extensive brochure that covered all aspects of Ebola, available to take home and with detailed medical, easy-to-understand explanations, including on how the response works.

Health promotion material was often in French (with some in Congolese Swahili) – a study in Butembo/Katwa/Kalunguta (CASS, n=559, October 2019) found only 5% spoke French while in Goma 23% (CASS, n=400, August 2019) preferred receiving information in French. Language across the Ebola area is diverse.[12] A survey in Mambasa and Butembo/Katwa/Kalunguta found that while a large majority used Swahili at home as their main language there were many variations (in spelling, loanwords, pronunciation and grammar) between Congolese and localised Swahili; for example, a qualitative study in Beni (where localised Swahili is the preferred language) found certain terms (headache and health centre) did not translate between the two. In a separate Beni study, Nande and Lingala were identified as important languages for people not fluent in localised Swahili, whereas in Butembo 20% in the study spoke Kinande (CASS).[13] People across North Kivu asked for information in what they called "community language", using words and concepts they were familiar with; *"For Ebola, we need [materials] even in Nande, the local language, so that if we give a flyer to a grandmother she will understand too"* (Male pharmacist, Beni; TWB). Community members and health communicators in Beni also asked for more audiovisual communication (on vaccination, the process of referral to a transit centre, Ebola treatment centres, and procedures for a secure and dignified burial),

especially documentary videos shown by projector. To date, these audiovisual communication has been very limited in the response, but was acknowledged as an important way to address doubts about Ebola especially for young people (TWB).

There continued to be disbelief and scepticism about the "real" causes of the epidemic; studies by CASS found that 46% of respondents in Goma (August 2019) and 25% in Mambasa (September 2019) did not believe the epidemic was real, largely because they believed Ebola was introduced for political gain, a way to eradicate the Nande people and/or for business – widely known as *"the Ebola business"*. These findings were corroborated by the IFRC feedback data. Compared to June 2019 data more people in Butembo accepted the existence of Ebola and viewed it as a *"real disease"* however marked differences were seen in affected areas and risk areas. Rumours on the political origins of the outbreak persist (e.g., the previous Government created Ebola) and tend to increase when new cases reappear in areas where Ebola had been under control. For example, in Beni in November (Novetta), there were accusations that response teams were deliberately spreading the virus to maintain their jobs and profit financially, repeating a pattern seen elsewhere. People in Butembo (SCG, October 2019) and elsewhere (IFRC, September-November 2019) had started to think that Ebola had already been eliminated, and this increased levels of suspicion and rumours around new cases.

Knowledge of Ebola:

After more than a year of living with Ebola, knowledge of the disease had greatly improved in Beni, according to an analysis by TWB (September 2019); however without longitudinal data (none available during this reporting period) analysis of trends remains challenging. CASS studies showed that many people (47% in Mambasa) did not believe there were ways to stop Ebola transmission nor that it could be cured (42%). Knowledge of Ebola prevention in Mambasa centred heavily on hand-washing, not touching a dead body, not eating/touching a dead animal and not touching physical material of a person sick with Ebola. Knowledge of Ebola symptoms was also relatively high in Mambasa: fever, haemorrhaging/bleeding, vomiting, diarrhoea and headache being commonly recognised, however joint, muscle and abdominal pain were less well-known symptoms.[14] Notably, qualitative research by TWB suggested that openly discussing sexual transmission of Ebola may be considered disrespectful in some contexts, suggesting the need for skilful communication on this topic. In Goma, when asked about the best ways to prevent epidemic diseases in general, 67% mentioned hand-washing and 45% vaccination; only 17% mentioned isolation (CASS survey, n=400, August 2019).

Religious beliefs continued to play a role in community understandings of the virus; according to qualitative research by World Vision many people believed the epidemic is linked to an evil entity or force, biological warfare or caused by transgressions in customary values, and requires animal sacrifices to end. Media monitoring by Novetta (October 2019) found that rumours circulating on WhatsApp channels in Butembo/Katwa and Beni/Mangina focused heavily on Ebola being spread by physical objects distributed by health authorities: Ebola and measles vaccines, food kits, thermo-flashes, water and mosquito nets. This may have long-term consequences for trust-building; for example, focus groups in Katwa and Kayna found that men believed measles and polio outbreaks were being *"created"* by the response staff to enrich themselves, according to data from SCG in October 2019.

As communities and the Ebola response itself learns and adapts, new dynamics, knowledge and interpretations have emerged that raise important questions for communities; increasingly they requested explanations, and not just instructions. As qualitative research in Beni showed: *"people generally understand the basic information. However new information and details seem to contradict what had been said before"* (TWB, September 2019). One of the most obvious examples concerned eligibility for vaccination. Initially, pregnant women and people with chronic illnesses could not receive the Ebola vaccine, but that changed, so people wanted to know why vaccination stopped posing a risk to those individuals. Another example had to do with people's perception that Ebola is caused by wild animals; as mentioned in a focus group in Katwa (SCG, October 2019): "*We were told that the virus is transmitted from humans by wild animals. But my children pick up and consume the leftovers of guavas that bats fall without [being] contaminated. And even the wild meat has been banned, it sells everywhere but there are no new recorded cases linked to the transmission of the animal to man."* Communities asked for up-to-date, precise and detailed information that addresses their questions in real-time. Otherwise they would begin to question other information, rumours start and misinformation spreads. The most sought-after information, according to the results of the TWB study in Beni in September 2019, concerned medical knowledge and the characteristics of Ebola, vaccination, treatment, and burials. Interviewees asked for detailed explanations that go beyond *"If you go early to the ETC you can be cured",* or *"Ebola is transmitted by fruit bats."* Survey respondents in the CASS Butembo/Katwa/Kalunguta, Goma and Mambasa studies (August-October 2019) raised questions about how to protect themselves, what to do if they get sick, who gets the vaccine, how the vaccine works, what treatments are available at ETCs, how Ebola is transmitted, details about safe and dignified burials and when Ebola will end. Communities also wanted hopeful messages that are attuned to the downward epidemiological trends in Beni and elsewhere to decrease fear and point to an end of the epidemic: *"People think it's coming to an end. We already socialise more. At least we can breathe: it's not killing at the same rate as before. Dr Muyembe said [Ebola] will be finished in four months. An end to the disease - that promise is still in people's hearts"* (focus group, Beni, TWB, September 2019).

Knowledge of Ebola among health workers and communicators:

A CASS survey with 68 private, public, hospital, pharmacy and traditional practitioner staff in Mambasa and Mangina (September 2019) explored health worker knowledge and practices. Generally, knowledge of some symptoms was high: >80% for headache, bleeding, fever, diarrhoea and abdominal pain, although lower for joint pain (58%) and muscular pain (31%). When asked how Ebola spreads, 73% mentioned contact with the bodily fluids of a sick person and 60% touching a person who died from Ebola; none mentioned sexual transmission; 63% emphasised that Ebola can spread in health structures, 72% also mentioned it can spread "anywhere" and only 3% mentioned burials as specific sources. Only 20% of staff from Mambasa and 21% from Mandima reported feeling capable of explaining Ebola to patients and their community, and there were important gaps mentioned in care/treatment, safe and dignified burials, vaccination and transmission. While all staff from the private and public clinics and hospitals reported having been trained on Ebola, only 13% of respondents from pharmacies and 14% traditional practitioners reported this. Health communicators in Beni (TWB qualitative study, September 2019) highlighted the need for trainings to be held in languages local people understand such as Swahili and Nande as well as French: *"Many training sessions were in French, although many didn't have good enough French to understand. They just looked at the pictures and had a laugh until it was over"* (Health worker, Beni, TWB, September 2019). Few health staff trainings, in the Mambasa/Mangina CASS survey (September 2019), took place inside the health facility, which improves comprehension and application. Health staff asked for training on nearly all aspects of Ebola: the origins of the virus, symptoms, prevention and control as well as updated information on vaccination, referral procedures and new treatments. According to the TWB study in Beni (September 2019), without detailed knowledge of the response strategies, many health communicators (who do not always have a background in health) could not answer questions from the community, their attempts could even contradict official statements and made them look unprofessional or

arrogant: *"I'm ashamed, because I can't answer their questions, and all the frustration of the population is turned against us communicators"* (Female health communicator, Beni, TWB, September 2019). Health communicators also reported to struggle with finding the right words to translate key terms, and find the many abbreviations used in the response as being among the hardest (e.g., SBDs, ETCs, IPC, etc.).

Prevention behaviours:

Two CASS surveys, in Mambasa (n=393, September 2019) and Goma (n=400, August 2019), asked respondents whether they had changed behaviour to prevent Ebola infection; most had: 92% and 72% reported more frequent hand-washing, 51% and 27% the avoidance of shaking hands, 23% and 25% avoidance of all physical contact, although only 15% and 9% avoided sick people, 14% and 97% avoided funerals. In a separate CASS survey, 23% in Butembo and Katwa (n=792, November 2019) reported there were places they had stopped going because of Ebola, mostly burial sites / funerals and health facilities. There continued to be calls for more hand-washing stations at community level in markets, schools and churches: *"When we ask parents themselves to buy these handwashing devices in schools, it sends a message that the state has disengaged"* (World Vision). The IFRC community feedback data highlighted concerns that some officials were not following hand-washing protocols: *"Why don't military vehicles and those of the political administration authorities stop at the check point so that people can wash their hands?"* .

With over 1,000 survivors, and although overall risk was deemed to be low, an important emerging concern was the prevention of Ebola through sexual transmission; a small study by CASS (Beni, October 2019) with Ebola survivors (11 men and 5 women), sex workers, health workers and their partners explored condom use and prevention; all survivors had been sensitised on the use and importance of condoms, 4 (male) survivors rated their risk of infecting their sexual partner(s) with Ebola as very low and only 2 assessed their risk as very high: *"The risk to me is 0%, because in my opinion the sperm does not contain Ebola. I have evidence. There are my healed friends who have sex without a condom and their partners are in good health."* Most of the men reported using condoms, even though many had not previously used them, but 5 out of the 6 of the women survivors said that they do not use condoms. As one women survivor reported: *"No, because I am not authorised, I have to use other means of protection, even for family planning, in church we are taught a good way to do it without the use of condoms."* The study found that of 87 comments made on condoms, 54 were positive and 33 were negative – dislike of condoms mostly related to the texture of the lubricant and various religious beliefs.[15]

Care-seeking and home care:

Ebola symptoms continued to be confused with other more common illnesses by community members with important implications for early presentation and care-seeking. When asked about their health problems, survey respondents (CASS studies) in Butembo/Katwa/Kalunguta (n=559, October 2019), Mambasa (n=393, September 2019), and Goma (n=400, August 2019) mentioned malaria (78%, 84%, 82%, respectively), diarrhoea (45%, 51%, 30%), fever (46%, 60%, 0%), and measles (19%, 26%, 0%) – conditions frequently associated with Ebola – while 19%, 38%, 0% mentioned the virus directly. People cited the symptoms of Ebola but did not understand how common symptoms had become associated with a deadly disease: *"We had fevers and colds before, but now if you have one of these signs you need to hide. We always have colds in Beni, but today having a cold is a sign of Ebola. We don't understand that."* (Beni, TwB, September 2019). When asked what symptoms would motivate parents to seek care for their under 5 years child in Butembo (CASS, n=559, October 2019), many mentioned 'big fever', vomiting and diarrhoea, while far fewer mentioned headaches, intense fatigue or bleeding. In Mambasa, most respondents (CASS, September 2019) also mentioned fever, diarrhoea and vomiting with fewer mentioning intense fatigue, headache and joint, abdominal and muscle pain. In the Mambasa survey, 34% would go to a public health centre, 33% pharmacy, 24% modern medicines at home, 12% private clinic and 5% herbs in the first 2 days of having a fever. Women predominately care for the sick both at home and assist family members at health facilities. In Butembo/Katwa/Kalunguta (CASS, n=559, October 2019) 91% of respondents reported a change in treatment routes (for symptoms of malaria) since Ebola and more than half saying they waited longer or avoided health facilities as a result of the outbreak. Fifty percent of the participants in the Butembo/Katwa/Kalunguta survey believed that parents have less confidence in doctors' care for their children than before Ebola and feared that medical professionals will confuse the symptoms of Ebola with other diseases. This has motivated self-medication, although financial reasons and other factors also play a role: *"During Ebola, people strengthened self-medication. They do not want to go to the health facility so as not to be transferred to the CTE, but before Ebola, they self-medicated for lack of financial means*" (Interview, Butembo, CASS, October 2019). Half of respondents from Mambasa and Mandima (CASS, n=68, September 2019) believed that a main reason the epidemic persists is because people continued to hide their sick. In the Goma CASS survey (n=400, August 2019), 67% knew about isolation as a strategy for disease control, of which 85% reported that it was a good strategy, however, 82% also mentioned that isolation far from the community was the main reason people would refuse.

Engagement with public and private health facilities:

Health facilities continued to report inadequate equipment and IPC protocols; only about a third (36%) of health facilities in Mambasa and 17% in Mandima (CASS, n=68, September 2019) felt capable of detecting an Ebola case or preventing Ebola transmission. Social media analysis by Novetta indicated that regional leaders touring health facilities in Butembo and Katwa claimed many were still "dirty" and were not adhering to appropriate hygiene best practices to prevent nosocomial infections. In the same CASS survey, many health staff reported that while they had Ebola protocols, for example for entry temperature assessments (74%), hand-washing stations (68%) and triage (51%), very few had an isolation room (18%) or ability for systematic disinfection (18%). Health facilities continued to lack water, for example in Mambasa/Mandima 91% of facilities did not have regular access to water.

Free medical care continued to be offered in some health facilities to boost attendance, although proximity, trust and perceptions of quality were often more important aspects of choosing health services. This did not mean financial considerations were not sometimes dominant too; in Goma (CASS, n=400, August 2019) 75% of survey respondents stressed that money was the main factor that prevented access to health facilities. A rapid qualitative study in Biakato Mines, Ituri, by CASS (October 2019) found that care was based on "knowing" staff, who lived in the community and were trusted, even sometimes accepted in-kind contributions instead of cash for medical care. This point was reiterated in Butembo: *"Because here at home people prefer to go to a hospital where they will be treated by doctors they know. So, when they arrive in a health facility and find people they don't know and who don't even speak their language, they are afraid. That's why they hide in homes no matter what symptoms they show"* (World Vision, September 2019). However, many respondents in Butembo (CASS, October 2019) believed that since Ebola, health services had changed for the worst, due to patients being sent to ETCs indiscriminately, lower quality care and a general fear of dying or being killed by health staff. A separate study, in Mambasa and Mandima (CASS, September 2019) also reported reduction of patients due to Ebola. The data identified various gaps in

engagement from health facilities, including a lack of inclusion of traditional healers in the response (Mambasa, CASS, September 2019). The militarisation of the response was also seen as particularly problematic, although there were reports that this had reduced in Butembo following the reduced case count, which had led to an increase in attendance at health facilities, (SCG, October 2019). There were also strong concerns about the consequences of Ebola on resurgent numbers of malaria, measles and cholera cases, which citizens felt were being neglected at the expense of Ebola.

Popular distrust had eroded relationships between communities and the medical profession: *"We have become enemies of the population…this is because of the trauma that is already ingrained in the heads of our people. They are really traumatised. They think we are not really people; they are intimidating us."* (Anaesthetist, Beni, TWB, September 2019). Health personnel in Mambasa and Mandima (CASS survey, September 2019) had organised Ebola-related activities (mostly educational talks); however, many also reported that community members had less confidence in them due to Ebola and not feeling safe to speak openly about Ebola to patients and their community. The wearing of personal protective equipment (PPE) had earned doctors and health workers the title *kinyawu* ("monster") (TWB October). Qualitative research in Beni found that when visiting a health facility, people were actively trying to lower their temperatures. A senior physician in Beni highlighted the *"numerous"* doctors and nurses that still denied that Ebola was real, suggesting that some medical practitioners may have been disseminating inaccurate or unfavourable information (Novetta, September 2019).

Perceptions of Ebola treatment and ETCs:

As of January 5, 2020, there were 11 operational Ebola treatment centres (ETCs) and 25 Ebola transit centres located in the provinces of North Kivu, South Kivu and Ituri.[16] On 4 October, the 1,000th Ebola survivor was released from the Mangina ETC, not far from where the first cases were identified in August 2018; similarly in October, the Butembo ETC cleared its last remaining Ebola patient, which provided an opportunity to celebrate successes and emphasised the need to increase prevention and control activities to avoid future cases. Prior to and after these events, Ebola survivors were active in community media in raising awareness about the importance of early presentation to ETCs to increase chances of survival, address long-term perceptions about poor care and conditions at ETCs; as one Ebola survivor stated in local media, "*Me, for example, I lost 12 members of my family, including my wife, we had resistance, and I too was affected by the virus, and what is being said in the community is wrong. To resist the virus [is wrong], we received a good treatment at the ETC, and today I am alive"* (Novetta, September 2019). However, it is not clear how well the successes in treatment have been communicated outside specific media windows. In Mambasa, the surveys with health staff (CASS, September 2019) found that nearly all believed Ebola could be cured but this belief was much lower at community-level. In Butembo and Beni, a short survey by Novetta found that 76% (n=292) and 60% (n=294) believed that Ebola treatment drugs and early presentation, respectively, would help chances of survival. Media monitoring by Novetta found that information about treatment remained minimal from September-November 2019, and the treatments themselves, often referred to as "the cure" were regularly confused with the release of the second J&J vaccine (which received more local media coverage). Qualitative research in Beni by TWB in September found that community members had many questions about the differences between the four drugs that were being tested at the beginning of the response and why two were ultimately chosen, and media monitoring by Novetta in November in Beni found numerous instances of people believing that you must have social connections to response officials to receive the proper drugs.

Early presentation to ETCs is key for Ebola treatment effectiveness and chance of survival. To investigate perceived explanations for delayed presentation at ETCs, CASS conducted a qualitative study in Beni (Bustil, Kasanga), Mandima (Bikato Mines) and Mabalako (Aloya, Mangina) (September 2019). Participants across all health zones spoke about treatment and survival as being the main motivator to present quickly to ETCs. In Bikato, where suspected patients presented on average more than seven days since symptom onset, they spoke of response sensitisation activities and trusted locals working for the response as motivators to present early to ETCs. Fear of ETCs and of dying were the most common barriers to early presentation. In Mabalako (Mangina), respondents highlighted specific barriers related to fees for transport and poor perceptions of care. In Bikato Mines, rumours and lack of information were additional common barriers cited. An example was given of advice being given in a church in Bikato not to go to CTEs and that Ebola was a demon. In a second qualitative study, respondents spoke of ETCs as part of the "Ebola business" conspiracy. They described continued rumours about what "really" happen inside them, including organ extraction for sale: *"Ebola does not exist. When you arrive at the ETC, they inject products that kill them"* (CASS, September 2019). Other studies have identified a continued lack of information about ETCs: disinformation from leaders, lack of knowledge of symptoms and lack of understanding of the ETC; confusion about the differences between ETCs and transit centres (TWB, CASS, Novetta). In Butembo/Katwa (CASS, October 2019) people also lacked confidence in Ebola tests, because symptoms are not clear. Use of a language that people do not understand increases fear; for example, 'isolation room' is interpreted by some to be a place where you *"wait for death"* and *"ETC is a word that scared us. We're really afraid of this word."* (Pharmacist, Beni, TWB, September 2019). Warning about fraudulent ETCs by the DRC Ministry of Health also reaffirmed rumours about fake treatments (Novetta, September 2019).

Surveillance:

As cases reduce in eastern DRC, there is more intense public scrutiny around each suspected Ebola case. Recent new case numbers in Beni were a point of contention between local reporters, with claims of discrepancies between government reported figures and Ebola responders' data (Novetta, November 2019). This can serve to reinforce community misinformation about the motivations of response staff, since reporting is viewed as a way to make money by response staff who must report certain numbers to keep their jobs. Although efforts have been made to reduce this, qualitative research by World Vision (September, 2019) found that perceptions of surveillance teams still focused on the negative effects of large numbers of vehicles and noisy *"flashy"* entrances, as teams *"descend into"* and *"invade"* the community to respond to an alert. This was a major source of stigma and anxiety: *"When we make field trips to find and test suspicious cases, as soon as we arrive, a crowd of children form in front of the house of the suspicious case shouting 'he has Ebola, he has Ebola'..."* and *"No one will approach a former patient or contact case in the neighbourhood anymore."* (World Vision, September 2019). Qualitative research in Beni (TWB, September 2019) found that specific terms have also generated confusion: a "cas" (case) was associated with the Nande term "ka" (a criminal of little value) while a "cas contact" (contact case) was associated with a person with HIV and prostitution: *"We didn't understand the language of the foreign doctors at first. For example, when they spoke of 'contact' without giving any more explanation, we wondered …what kind of contact ... telephone number? Sexual contact?"* (Nurse, Beni). In October, local WhatsApp channels monitored by Novetta suggested that the thermo-flash tool being used at checkpoints was inaccurate and caused many who did not have fevers to be held for testing, and there was also evidence of people advocating swallowing paracetamol to lower their body temperature before passing through the gate.

Knowledge and understanding about the Ebola vaccine:

From 8 August 2018 to 4 January 2020, 261,285 persons were vaccinated with the rVSV-ZEBOV-GP Ebola vaccine.[17] In response to a request from the vaccine sub-commission, in September 2019 the CASS conducted a synthesis of data gathered between August 2018 and September 2019 to identify targeted recommendations to further strengthen their operations.[18] This synthesis included 14 CASS studies (3,061 participants), 18,148 points of community feedback from IFRC and 2 studies from TWB (216 participants). Key findings indicated that amongst health care workers and communities there were high levels of awareness of the vaccine and belief that it was protective. The study highlighted a need for targeted information to be developed, using different media, that focused on potential side effects of the vaccine, explanations of how it works and about the process of ring vaccination and eligibility. Mistrust of the vaccine stemmed from misunderstandings about how it works and from negative experiences such vaccination by strangers, health workers unable to answer questions, and sometimes, the presence of police. Implementation of recommendations by the sub-commission is being tracked through the CASS MONITO system.

A study to better understand concerns of community members in Bikato Mines, Ituri (October 2019) investigated low participation in vaccine programmes in Lalia and Mupanda quartiers, and identified fear, rumour, uncertainty, perception of injustice and lack of confidence as key factors in reluctance to engage with the programmes. Short surveys by Novetta (n=450, September-November) in Butembo and Beni found that self-reported reasons why respondents would refuse to be vaccinated against Ebola included: low confidence in the effectiveness of the vaccine, safety concerns, side effects, chronic health conditions, pressure from family members, general distrust in vaccines and fears that the vaccine give you Ebola. There were continued rumours and fears that the vaccine can lead to abortions, disease, 'mental disorders' and death: "*Everyone who received the first vaccine will become crazy after five years"* (SGC, October 2019) *and "We refuse to be vaccinated for fear of dying after 5 or 10 years, which is the lifespan of the vaccinated*" (CASS, October 2019). There were also concerns about whether citizens should take the vaccine now that there is a "cure" (treatment) (CASS, SCG, Novetta, September-October 2019). Participating in the vaccine was seen by some as participating in the "Ebola business": *"I have been told by my pastor that it is a sin to have the vaccine. I do not listen to the Ebola business, I listen to my pastor so I do not sin for taking a fake vaccine"* (Novetta, October 2019). Health staff have been a major focus of vaccination campaigns; in Mambasa (CASS, September 2019), 100% of private and public clinics and hospital staff reported to have been vaccinated although only 13% of pharmacy and 50% of traditional practitioners had been, In Beni, 6/7 of the spouses of cured patients had been vaccinated and 13/18 of female sex workers (CASS, October 2019). Motorcycle taximen were visible in their support of vaccination in local broadcast and print media in November during an effort to vaccinate public transit workers in Beni (Novetta).

Between its introduction on 14 November 2019 and 4 January 2020, 4,802 people had been vaccinated with the Ad26.ZEBOV/MVA-BN-Filo (Johnson & Johnson/J&J) vaccine in Karisimbi Health Zone of Goma. Outside the trial area, multiple studies found that citizens expressed concern and wariness about the introduction of a second vaccine, and displeasure with the idea of another experimental trial operating in the region. They had questions about the compatibility of the two vaccines, wondered whether the first vaccine had become less effective and found it confusing that there were two vaccines for one disease, as this appeared to be at odds with normal medical countermeasures for other vaccine preventable diseases (CASS, October 2019; Novetta, October 2019). With the start of the J&J vaccination campaign in Goma, inaccurate claims circulated in early November that pregnant women would become ill and die if they received the vaccine (Novetta). The experimental nature of the various Ebola vaccines has remained deeply problematic for many: *"We were told that the vaccine is still in the experimental phase, and I will never forget that word in my life. When I checked in the dictionary, I realised that I had become a guinea pig, and I immediately had doubts…I had become part of a test, and a test can fail"* (community outreach worker, Beni, TWB, September 2019). A prominent civil society organisation, La Lucha, claimed that the second vaccine was a conflict of interest as it "*favours research instead of saving lives*" (Novetta, November 2019). In contrast, local media highlighted that administration of the J&J vaccine in Goma by Médecins Sans Frontières (MSF) was happening in a "*calm and very respectful way*," "*without incident*"; a significant majority of voices in regional media coverage responded favourably to MSF's leadership. Messaging by MSF on 23 September, however, calling for more transparency from the WHO in regard to vaccine distribution was used by some to claim the second vaccine was not necessary and led to a recycling of previous perceptions that WHO and MSF were in a "*turf-war*" for operational control of the outbreak, which may attenuate public perceptions that WHO is complicit with the "*Ebola business*"*: "The people in the response have already brought 2 vaccines. One was made by Dr. Muyembe and it's the best vaccine they give to whites and rich people. Another was made by whites in complicity with Kabila to exterminate the eastern population where they want to exploit gold and oil."* (Novetta, Lubero, October 2019). The Russian government's announcement, on 12 November, that they would provide 5,000 doses of the Russian EpiVakEbola vaccine to be tested alongside the two other vaccines only furthered these negative public perceptions: *"If this is true, I think personally that the government is joking with the minds of the people"* and, *"this [will] show people that Ebola is really business"* (Novetta, November 2019).

Community experience of Ebola vaccination programmes may not have impacted on public acceptance of routine childhood vaccination, including new vaccination campaigns for measles and polio conducted in September and October 2019. CASS surveys in Butembo/Katwa/Kalunguta and Goma (October and August 2019), found that 90% and 81% of participants (n=559 and n=400) reported confidence in childhood vaccines. However, in the Butembo/Katwa/Kalunguta study, 50% reported that routine vaccination outreach had stopped and 17% claimed they now fear all vaccines as a result of the introduction of the Ebola vaccine: *"Our children have missed their vaccines…it was a way of punishing women for being [showing resistance] to the actions of the response"* (Interview, Butembo, CASS). New prevention measures (i.e. single use gloves) and concerns about nosocomial transmission meant that health workers were taking longer to conduct routine vaccination (CASS, October 2019).

Burial practices:

As of 6 January 2020, 20,840 safe and dignified burial (SDB) alerts had been notified through the Red Cross database, of which 18,790 (86%) had been responded to successfully by Red Cross and Civil Protection SDB teams and community harm reduction burial teams.[19] Data continued to show relatively high community acceptance of safe and dignified burials. Qualitative research by World Vision (September 2019) and SCG (October 2019) identified a significant decrease in community resistance and rumours (about stealing organs, for example) as SDBs teams sought to better involve families and communities in the burial process: *"Yes, before we were thrown stones and the family thought we were cutting off organs like breasts, genitals but these were rumours. But when we started showing the body to the family, they understood that it wasn't about that..."* (World Vision). Focus group participants in Butembo reported positive changes in the practices of the SDB teams, including customary practices, such as dressing the corpse before burial, untying braided hair, washing the body of the deceased. Such practices continued to be adapted to address concerns about Ebola spread and contamination (SCG and World Vision); however, the adapted burial practices were used with some consternation: "*You know for us*

Nandes, when we are crying over a dead man, we touch him and talk to him, giving him the message that he will bring to other loved ones who have died before, and that brings us some consolation in a way. So when we are forbidden to touch the dead it breaks our hearts more and more; so we take it with a lot of regret..." (World Vision). Concerns also remain regarding the use of body bags, which were believed to keep the soul from being released to the afterlife and community members continued to express confusion about why swab tests were needed for all deaths, even when the non-Ebola related cause of death was well-known to the family (SCG). Qualitative research by TWB (September 2019) found that community members in Beni did not understand the term "swab" while other terms could be interpreted differently than intended, such as safe and dignified burial ("death after mutilation") and community death ("death of a community"). The development of a new cemetery by Katwa city hall was interpreted as a sign that the response was preparing to kill further community members through infecting them with Ebola (SCG). SDB team members and caretakers of cemeteries expressed concerns about their own security post-Ebola as some had been threatened as accomplices to the response.

Survivors and psychosocial support:

Survivors continued to be major advocates for addressing community misinformation and generating support for response teams, with many employed in patient care and community engagement. Traditional and social media monitoring by Novetta (September-November 2019) showed community support for survivors, although negative perceptions tended to receive much more attention. Community members reported a lack of guidance to monitor survivors after discharge and a wide range of beliefs about the possibility of survivors infecting local communities, including calls for a *"camp for isolation"* for survivors to remain separated from society for a period up to 500 days to ensure no futher spread of disease (Novetta, September-November). Isolated cases continued to be reported in local media that in Beni, Ebola survivors were re-infected months later and die; this damaged survivor reintegration as communities questioned whether survivors were really immune and added to scepticism about the accuracy of Ebola tests: *"One survivor told me it seems that those survivors who are dying of Ebola nowadays show that their first test case result was wrong, it was not Ebola, that they survived of another disease"* (Novetta, November). A short survey by Novetta (September-November 2019) in Beni and Butembo found that 37% (n=300) would not eat a meal with a survivor. Survivors were seen as *"accomplices"* of the response; an extreme rumour suggested that survivors deliberately have unprotected sex to spread the virus for money (SCG, October 2019). Qualitative research with survivors in Beni (CASS, October 2019) found that some continued to have unprotected sex and highlighted the need for couple sessions with survivors to ensure that both partners know the importance of using condoms. Qualitative research by SCG (October 2019) suggested that many survivors had lost their jobs due to fears of contamination and many faced rejection, in some cases, by their families: *"It hurts when I walk past the school where I was teaching, and the children who recognise me start screaming in my direction: Ebola, Ebola!" (*Survivor, Novetta, October 2019). Ebola orphans and widows continued to suffer trauma and experience discrimination by their communities. IFRC community feedback data also documented the continuing community-level psychosocial impact of the outbreak: *"Currently we live in a turbulent period where the love of others is diminished due to EVD".*

Terminology used in the response:

In the context of distrust and fear, the language spoken and descriptions used have important subtle influences on perceptions of trust and identify. The use of Lingala (the language of Kinshala and the military, and also associated with violence against civilians in the region, i.e. the massacres) in the first months of the Ebola response was criticised as one of the main reasons why people avoided Ebola response teams: *"We are afraid of Lingala in Beni town. Those who speak Lingala, we say they come to butcher us"* (Laboratory technician, Beni, TWB). Research by TWB (September 2019) found that many of the specific medical terms used in the Ebola response were in French and not consistently translated and explained in other languages. This research found that some Beni residents misunderstood seemingly simple medical terms in French, like "allergic", "virus" or "molecule" and local people consider many of the terms used in the Ebola response harsh, and so react negatively to them. Community members continued to ask for explanations of words perceived as stigmatising or frightening such as "suspected case", "isolation," or "ETC." In Beni, focus group participants asked for health information in localised Swahili and the Nande of Beni to increase trust and further localisation of the response.

In the absence of standardised translations, health communicators used French words to discuss Ebola, even when speaking a different language. For people who were not fluent in French or were less educated, seemingly simple terms like *cas* probable ("probable case"), *infectieux* ("infectious"), *guéri* ("cured"), and *épidémique* ("epidemic") remain unclear and hinder correct understanding. It was found that a key term like "virus" was still not universally understood. Other terms caused confusion due to their technical nature and lack of detailed medical explanation. Even if people understood medical concepts like "molecule" or "experimental vaccine", the meaning and implications of these words in the context of the Ebola response remain vague. Community members also expressed frustration about the language competencies of response staff: "*When you're ill, you're there with staff that speak only French. You don't understand each other, and then the trust is gone. He'll try to speak a Swahili that I don't understand. He may write things in his notes that I don't understand."* (Woman, Beni, TWB, September 2019). It was suggested that such language could make patients and families feel insulted or concerned that staff were hiding things, reinforcing social distance, power relationships and the perception of coercion to experimental therapies and therapeutics. It also generated confusion and lack of trust about the course of events and what should be done: *"In medicine they have very many terms. If you have something like malaria, they don't call it malaria, they tell you it's 'paludisme'. If you have never been to school, you won't understand a thing and you get confused. It's a reason why people no longer go for treatment. You're afraid that once you're there, they'll start using those words of theirs, and then they'll take you away without asking you."* (Female resident, Beni, TWB, September 2019). The study also highlighted that greater sensitivity is needed regarding aspects of non-verbal communication including body language and gestures, appearance and cultural norms and manners. For example, keeping a cap on while speaking was considered extremely rude, while women in skinny jeans were embarrassing (TWB, September 2019). Specific images on posters and fliers were seen as inappropriate or were misinterpreted; for example, an image showing a woman in a short skirt as part of the safe and dignified burial team or a man with a very badly drawn face. Colours were also seen to have specific cultural meanings. On the "old" Ebola posters red and gold/ yellow were the main colours; these reinforced perceptions that Ebola was a business: red symbolised death, whereas gold/yellow represented wealth (TWB, September 2019).

Community perceptions of the response:

Citizens across the region continued to express the need for adequate resources in the fight against Ebola; with diminishing cases, public sentiment was heavily influenced by the threat of resurgent case numbers and spread. Novetta found more positive voices emerged over this reporting period in Butembo and Goma compared to Beni, where there was a negative shift due to increased violence and Ebola resurgence. CASS surveys in Butembo/Katwa/Kalunguta (October 2019), Goma (August 2019) and Mambasa (September 2019) found

that a relatively high proportion of community members (>60%) had interacted with response staff. Compared to June 2019, SCG (October 2019) found more support of the Ebola response in Butembo as a result of greater community involvement, capacity building and engagement (with health authorities, civil society leaders, leaders of women's and youth organisations and local leaders) as well as the decline in new cases. There has also been continued community engagement with pressure groups, such as Veranda Mutsanga, as well as Mai-Mai militias in Beni in October, despite ongoing violence in the region (Novetta). Media and local medical professionals provided very favourable coverage of MSF in October and local citizens praised the WHO for not evacuating when security issues threatened operations (Novetta). There was also significant praise in September for the instalment of Dr Jean-Jacques Muyembe (*"doctor for the people"*) as the head of DRC's Ebola response efforts, who continued to receive significant positive coverage over this reporting period (Novetta) as one of the most trusted public figures in the response. Demilitarisation was praised in some areas of Beni and Butembo, and highlighted as a success of community engagement, although this was also interpreted as a sign of de-emphasising the threat of Ebola by local government (Novetta, October 2019).

However, there continued to be calls in social media for greater localisation of the response, including for national medical officials to assume full responsibility of the response as continued foreign presence in the region becomes less welcome (Novetta, October 2019). Perceived exorbitant salaries of personnel have resulted in requests for more transparent human resource recruitment systems to address what some see as incompetent staff (World Vision; SCG) which exacerbates community hesitancy and refusals. According to data from SCG (October 2019), the number of private luxury vehicles used by response teams was reported to have reduced in Kayna, Karisimbi and Nyiragongo, following long-term community criticism, while in Katwa they were reported to have been replaced largely by motorcycles. Comments about social distance continued, although it was hard to tell if these were retroactive, when events occurred and how much current staff continued to be perceived as 'outsiders': "*When the doctors arrive and we don't know them, their clothing isn't appropriate and respectful, with their big hats, kanga dadi (skinny jeans) and their Motorolas [...] we are afraid to approach them."* (Female, Beni, TWB, September 2019). Despite these negative reports, aggregated data from short surveys by Novetta (September-November 2019) in Butembo and Beni found the majority of respondents supported foreign medical professionals and response teams. Respondents from Beni reported that teams behaved well and provided high quality information, (CASS, September 2019); however less than 40% of community members in Butembo/Katwa/Kalunguta (n=559, October 2019), Goma (n=400, August 2019) and Mambasa (n=393, September 2019) reported understanding how the response functions and the role of the different interventions, while, among people who had had interactions with response staff in Mambasa, only 40% reported they had been treated well and 75% did not believe response staff had been sufficiently informed about Ebola. Local media monitoring by Novetta (October-November 2019) revealed problems with the motivation of response staff which has been associated with the extended periods they have gone without pay, which led to calls for strikes in Butembo in November. In Beni, there were concerns in October about a general reduction in effort by response partners, the layoffs of staff, lower local radio broadcasting and reductions in community sensitisation and information sharing in specific communities (Novetta).

Perceptions about the economic impact of the response varied and, according to a CASS survey in Butembo and Katwa (n=792, November 2019), were almost equally divided among those who believe that the economic situation has improved and others who believe it has deteriorated. For example, 54% reported that there was a more money circulating in the community due to Ebola; however, 38% also reported spending more money on goods and services as a result and 34% believed the cost of food has increased. Most new economic opportunities were associated directly with the response (89%), although some respondents (>10% each) noted increases in the service sector, private business and as day labourers.

This idea that some response staff were deliberately prolonging the outbreak was widespread, with community members believing that local staff were complicit in the Ebola business: *"They have swallowed the money of the enemy who wants to exterminate us"* and *"A nurse who used to receive $100 a month now has $100 a day. Does this one really want the epidemic to end?"* (World Vision, September 2019). There continued to be rumours linking the Ebola response to profiteering, exploitation, genocide and political power: *"Ebola is satanic. The dead are sacrifices to strengthen Kabila's power. Those who work for Ebola are paid so much money because they are the ones who are helping Kabila and the white people to kill Congolese"* (Novetta, October 2019). The arrest of former Health Minister Dr Oly Ilunga was widely cited as proof of Ebola as a business while a new song and music video became a rallying cry for citizens who were opposed to response efforts in Butembo, which ties the outbreak to political and financial motives and has been widely shared in local media (Novetta, September 2019)[20]. Social media channels monitored by Novetta amplified rumours in October that food provided by NGOs for patients and contacts had been found being sold in local markets by response teams.

Population movement and the spread of Ebola:

Populations in Eastern DRC are known to be mobile. A survey by CASS in Butembo and Katwa (n=792, November 2019) found that 27% of respondents had at least one new household member arrive to stay with them and a similar proportion had a household member move to another health zone over the last 3 months. There have been repeated calls by some communities for more aggressive control of population movement and screening to end the epidemic, including isolating areas with cases (World Vision, September 2019). A rapid ethnographic study at three city entry/control points in Goma (which had its first Ebola case in mid-July 2019) found that many people refused to comply with handwashing and temperature reading with thermo-flashes due to the lengthy delays, disbelief in Ebola, it being a hassle and perceptions of the low quality of the water, "*[the water] is from the lake and chlorine can cause health problems*".[21] Staff at the checkpoints requested more modern hand-washing devices like they have in Rwanda. Checkpoints were unpopular, as one woman stated: *"On arriving at the checkpoint, we are tired with our heavy burdens on our heads or on our backs and we are subjected to the multiple harassments where we are forced to pay money to the police."* As noted in the IFRC feedback data, this may be common amongst officials and authorities. Some believed that the thermo-flash was a means to spread Ebola, and some were forced to comply with screening by the police – although there were many ways to bypass these checkpoints. As of January 5, 2020, the cumulative number of positive cases identified at Points of Entry (PoEs) and Points of Control (PoCs) was 30.[22]

Violence and insecurity:

During this reporting period, a major operation in North Kivu began by the Armed Forces of DRC (FARDC), following President Tshisekedi's campaign promises to eradicate the Allied Democratic Forces (ADF), which led to over 200 citizen deaths as ADF sought retributions and the surrendering of Mai-Mai militiamen. Citizens in the region believed the FARDC was ill-equipped for its mission against the ADF and called on MONUSCO to join the fight (Novetta, September-November 2019). Criticism of UN forces (which by association includes WHO) then reached a nine-month high, included accusation of responsibility for the deaths of protesters, lack of support for FARDC and negligence in protecting civilians; protests against MONUSCO led to the burning of a UN compound in Beni and

repeated calls for the UN to leave the region.[23] As the FARDC operation continued in Beni, community members called for more resources to be pulled from Ebola efforts in Butembo to be used for insecurity issues (Novetta). In November, Beni citizens pushed messaging that they wanted all Ebola response partners and MONUSCO to leave; one local source stated, *"The agents of the response are mobilising a lot of money…while massacres [that kill] for years are less interesting for the international community"* (Novetta, November 2019). Social media monitoring by Novetta found that attacks in the Mabalako health zone served as a prominent subject of discussion, with accusations that FARDC worked with local rebel groups to hinder the Ebola response.[24]

Violence continued to have major direct repercussions on the Ebola response and local populations. Threats to people who work for the response remained relatively common, with interviewees in Katwa and Kayna (SCG, October 2019) reporting that after the response some people would launch operation "*We know the house* " to attack the homes of those who worked with the response. Strikes, roadblocks and conflicts between different social groups continued to place response staff in challenging situations as support varies according to political expediencies. There were reports in October (Novetta) that some handwashing stations in high-risk ADF conflict regions were staged as ambush sites. The major FARDC operation underway in the Beni region since October was the dominant topic of interest in Beni and Butembo media, according to analysis by Novetta. After this ended, attacks and threats continued for ETCs and health facilities in and around Beni, and smaller attacks remained frequent and focused on treatment centres and handwashing stations, highlighting a continued resistance toward Ebola preventative measures even as new case counts have rapidly declined (Novetta, October-November 2019). In November, Novetta found that threats against journalists and radio hosts (who supported the response) resurfaced and culminated in the murder of a local journalist in Butembo while response structures and vehicles were destroyed in Mabalako Health Zone (allegedly by Mai-Mai, who were searching for a specific nurse they could not find).[25] Following a rebel attack in Biakato in late November that left multiple Ebola response personnel dead, minimal criticism of the Mai-Mai attackers was registered in social or traditional media channels (in comparison to the death of Dr Richard Mouzoko).

Studies included in the synthesis brief

Organisations	Study description	Timeframe of data collection	Methods
CASS (Cellule Analyse Science Sociale)	Rapid study on health knowledge, perceptions and practices in Goma	August 2019	N=400 questionnaire participants.
CASS	Rapid study on knowledge, perceptions and community practices in Mambasa	September 2019	KAP survey, n=393 respondents.
CASS	Rapid study on refusals to enter ETCs	September 2019	16 interviews with people who have refused to enter an ETC and 2 FGDs with community members in areas of Mandima, Mabalako, Butembo and Katwa.
CASS	Rapid socio-anthropological study: Observations of entry points and points of control in Goma	September 2019	Rapid ethnography (observations and informal interviews).
CASS	Perceptions and impact of the distribution of WASH-IPC kits (Beni, Mandima and Mabalako)	September 2019	115 individual interviews (Beni, Mandima and Mabalako) with households living around an Ebola case that had received WASH-IPC kits.
CASS	Rapid study on Ebola-related knowledge, perceptions and practices of health staff	September 2019	N=68 FOSA in Mambasa and Mandima.
CASS	Study on the perceptions and utilisation of condom use among survivors and their sexual partners in Beni	October 2019	5 FGDs and 57 interviews.
CASS	Perceptions on vaccination around Ebola vaccine rings in Laliya and Mupanda	October 2019	Group discussion with 120 community leaders and informal interviews with 30 young men and women in Lalia and Mupanda, Biakato Mines, Ituri Province.
CASS	Perceptions of the closure of the CODEMUCO health centre	October 2019	Interviews with 110 household members and one focus group with community leaders, Lalia quartier, Biakato Mines, Ituri Province.
CASS	Mixed method study on community health knowledge, perceptions and practices	October 2019	N=559 questionnaire participants and 34 key informant interviews and 1 FGD in Butembo, Katwa and Kalunguta.
CASS	Perceptions on the socio-economic impacts of Ebola	November 2019	N=792 survey participants (396 in Butembo and 396 in Katwa) in 35 health zones.
World Vision and the Catholic University of Bukavu	Study of the barriers to the low use of preventive measures during the Ebola epidemic, North Kivu	September 2019	52 in-depth semi-structured interviews in Butembo, Katwa, Beni, Kalunguta and Goma.
Search for Common Ground	Tupone Wote Pamoja (Healing Together in Eastern DRC) Conflict Scan, Butembo, North Kivu	October 2019	11 focus group discussions and 18 key informant interviews in Butembo (Kayna, Katwa, Nyiragongo, Karisimbi and Rwanguba).
IFRC	Online community feedback dashboard containing qualitative perception data.	September – November 2019	Further information about the system and methodology can be accessed at: https://odihpn.org/magazine/bringing-community-perspectives-decision-makingebola-response-democratic-republic-congo/
IFRC	Community Sentiments about the Status of the Ebola Outbreak Sept 23 - Oct 11, 2019	September – October 2019	Analysis of 689 community feedback comments.
Novetta	PALM Social Analytics	September-November 2019	Analysis of ~18,000 quotes from traditional media (radio, print, broadcast) and social media posts (WhatsApp, Facebook, Twitter) and n=450 survey participants across Beni and Butembo.

Translators without Borders (TWB)	Qualitative study to evaluate challenges of communicating about Ebola in Beni, North Kivu.	September 2019	25 focus group discussions and 20 open and semi-structured interviews with a quota-based sample of gender and age groups. Structured ethnographic observations and informal discussions from 9 health facilities in 8 health areas in Beni health zone.

References and notes

[1] SSHAP DRC social science and behavioural data compilations available from https://www.socialscienceinaction.org/resources/?_sft_region=west-and-central-africa&_sft_document-type=briefings&_sft_post_tag=ebola
[2] 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_s46.pdf
[3] https://www.unicefyouth.com/ureport
[4] Further information at https://odihpn.org/magazine/bringing-community-perspectives-decision-makingebola-response-democratic-republic-congo/
[5] All ranks are based on frequency and were provided by CDC and IFRC.
[6] "Hot" zones are areas with a case in the last 21 days; "Warm" zones, between 22-62 days; and "Cold" zones are areas with a case in 63 days or more.
[7] There were 926 'other' questions in September. '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. Questions in the 'other' category are regularly reviewed to identify new codes. Statements coded as 'other' included: Why did the health minister resign? Why are all patients available to the people of the response? Why when you can see someone bleeding, you can confirm that it is Ebola? Why don't you want the disease to end? If Ebola is not a business, why did you remove the first Doctor who was treating it in Beni? Why destabilise the population with Ebola? Why are the politicians involved in managing the EVD? Will the SDB, ECA, the hearse and the ambulance be available to the community after the epidemic? Why when building the ETC in Goma did this disease start?
[8] There were 1,087 'other' questions in October. Statements coded as 'other' included: How do I avoid Ebola when taking public transport? Why do you response workers have a lot of money? Does Ebola only concern us, the population, and not the authorities? Why when we ask a question to the person who works for the response if he also can get treatment at the ETC, he refuses to answer? Why does a response team member also refuse to go for treatment at the ETC? Why do the members of the response team who stay with the nuns defecate in the water wells that we use? Why do politicians seek to kill us by the crisis and Ebola again? Soon this disease will end. You will start to cut the throats of people in what policy? Why are the motorcycle drivers not affected by the EVD even if they are in contact with anyone?
[9] There were 913 'other questions' in November. Statements coded as 'other' included: You people in the Red Cross, are you sure about this vaccine we are supposed to take? Why are those who distribute food in the contact cases so dishonest? Can the animal that I kill also give Ebola? Why when you see someone bleeding do you confirm it is Ebola? Why do children catch measles when they are vaccinated, don't you see that white people are deceiving us? Why are we not eating smoked meat while animals are not dying from this epidemic? What are the diseases of dirty hands? Why destabilise the population with EVD? Can we eat locusts? How do you prevent the risk of contamination from animals to humans? How can we avoid EVD on public transport? We are sorry if the whites don't have work at home, but why do they come here?
[10] In the Mambasa survey, 83% preferred Radio Amkeni, 25% RFI and 25% Okapi, whereas in the Goma data radio station preference was much more diverse and included: RTNC, Yubi FM, RTCT, Radio Sauti ya Njili, Colombe FM, MISHAPI and others.
[11] For the full TWB report, please see: https://translatorswithoutborders.org/wp-content/uploads/2019/12/CR_DRC_BeniAssessment_EN_FINAL.pdf
[12] Regional and local language differences are important. According to language database (caid.cd), Nande is spoken by 90% and 78% of people in Lubero and Oicha. Swahili is the most common spoken language in all territories apart from Lubero. Kinyarwanda is spoken by 60%, 70% and 15% of people in Nyiragongo, Rutshuru and Masisi respectfully, while 80% speak Nyanga in Walikale. See the study by TwB for more details.
[13] The Nande of Beni Territory is very different from the Nande spoken in Butembo and Lubero Territories. Inhabitants of Beni have difficulties understanding the Nande spoken in Butembo. The Nande spoken in Beni borrows many words from Swahili. See the study by TwB for more details.
[14] These data and those about how Ebola is spread reflect trends found in other earlier CASS and HHI studies in different areas of North Kivu, as reported in previous SSHAP data synthesis briefs.
[15] It was unclear from the study results how long survivors were told to use condoms for; if they had a way to have their semen tested for the virus; and if guidance on condom use was different for female and male survivors.
[16] WHO, External Situation Report 74, January 7, 2020.
[17] WHO, External Situation Report 74, January 7, 2020.
[18] CASS, Key considerations for adapting vaccination campaigns. Presentation, September 2019.
[19] WHO, External Situation Report 74, January 7, 2020.
[20] See video on YouTube: https://www.youtube.com/watch?v=UsZYYbW6u_o&feature=youtu.be
[21] The city of Goma is a crossroads city on the border with Rwanda, with a lake port and a small airport.
[22] WHO, External Situation Report 74, January 7, 2020.
[23] The confidence of the Congolese in the ability of the mission to ensure security has waned in recent years. In answer to the question "Do you trust MONUSCO to ensure the security of your neighborhood/village?", only 15% of those polled in December 2018 by Peacebuildingdata.org replied 'yes'. The anti-UN protests may not be as spontaneous as they appear, but rather planned and financed by political operatives who are inflaming the situation.
[24] Further background analysis can be found in the Kivu Security Tracker of the Congo Research Group, https://kivusecurity.org/ Also see further discussion in: https://africanarguments.org/2019/12/11/adf-rebels-in-the-drc-why-are-locals-protesting-against-the-un-again/
[25] Monitored media content over the last nine months reveals that female nurses or medical professionals have been targeted in more than 70% of the reported cases of groups seeking to harm specific Ebola response personnel. In spite of this, attacks on male response personnel are covered by local media at a much higher rate (Novetta).

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 Olivia Tulloch (oliviatulloch@anthrologica.com) and Santiago Ripoll (s.ripoll@ids.ac.uk). Key Platform liaison points: UNICEF (ebraud@unicef.org); WHO (falerom@who.int) and (barryr@who.int); IFRC (ombretta.baggio@ifrc.org); Communication Commission in DRC (jdshadid@unicef.org); CASS in DRC (scarter@unicef.org); GOARN Research Social Science Group (nina.gobat@phc.ox.ac.uk).

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