

## Social science and behavioural data compilation (#4), Ebola outbreak eastern DRC, June-August 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 fourth data synthesis brief produced by the Social Science in Humanitarian Action Platform (SSHAP) and focuses on data published between June and August 2019. It builds on the previous three data synthesis briefs, the first focusing on data from August-October 2018, the second on data from November 2018 to January 2019, and the third on data from February to May 2019.<sup>1</sup>

At the time of publication (as of 6 October 2019), 3,205 cases had been reported (3,091 confirmed and 114 probable) of which 2,142 died.<sup>2</sup> The overall case fatality ratio was 67%, the same as the rate in the middle of June 2019.<sup>3,4</sup> The majority of the 73 confirmed cases identified between 16 September and 6 October were from the health zones of Mambasa (30%; n=22) and Mandima (23%, n=17).

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### Community feedback: themes and questions

Multiple organisations including the IFRC and the National Society of the Red Cross in DRC, UNICEF, WHO, Oxfam, FHI-360 other INGOs and local partners continue to compile community feedback and conduct 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.<sup>5</sup> The table below presents the five themes most frequently identified in the community feedback gathered by Red Cross volunteers between 1 June and 31 August 2019 (rank 1 being the most frequently raised theme).<sup>6</sup> During the reporting period 27,977 comments categorised as 'rumours', 'observations' or 'beliefs' were analysed. Issues related to the causes of Ebola, vaccine suspicions and non-acceptance and Ebola being a scheme of the government or others continued to dominate (similar to the first months of the outbreak August-September 2018). In the February-May 2019 period, concerns around the quality of the health system were also emphasised, and these issues continued to dominate feedback in the period June-August 2019.

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

	June 5,983 codings Beni, Bunia, Goma, Karisimbi, Komanda, Mabalako, Mandima, Nyiragongo, Oicha	July 11,597 codings Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Musienene, Nyiragongo, Oicha, Rwampara	August 10,397 codings Beni, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara
<b>Rank 1</b>	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
<b>Rank 2</b>	Ebola characteristics and consequences	Ebola characteristics and consequences	Ebola characteristics and consequences
<b>Rank 3</b>	Ebola is organised business	Ebola is organised business	Ebola is organised business
<b>Rank 4</b>	Critiques or observations of the health system	Critiques or observations of the health system	Critiques or observations of the health system
<b>Rank 5</b>	Ebola does not exist	Vaccine suspicions and non-acceptance	Vaccine suspicions and non-acceptance

Questions asked by community members were also reported as part of the community feedback. During the June-August 2019 reporting period, 30,128 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

	June 6,933 codings Beni, Bunia, Goma, Karisimbi, Komanda, Mabalako, Mandima, Nyiragongo, Oicha	July 12,241 codings Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Musienene, Nyiragongo, Oicha, Rwampara	August 10,954 codings Beni, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara
<b>Rank 1</b>	Ebola and its consequences	Ebola and its consequences	Ebola and its consequences
<b>Rank 2</b>	Vaccine	Response processes	Response processes
<b>Rank 3</b>	Response processes	Vaccine	Vaccine
<b>Rank 4</b>	Diagnosis, treatment, ETC, health system	Diagnosis, treatment, ETC, health system	Diagnosis, treatment, ETC, health system
<b>Rank 5</b>	Other questions <sup>7</sup>	EVD protective behaviours	Other questions <sup>8</sup>

The following is a selection of questions repeatedly asked by community members between June and August 2019 as documented in the community feedback gathered by the Red Cross and captured during qualitative research by CASS. Questions are clustered by key theme, not in order of frequency.

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

<b>Ebola and consequences</b> Vulnerability, spread and mortality.	Why has Ebola lasted so long when you said that Ebola wouldn't last three months? Why does Ebola disease last so long when we are following your advice? Is Ebola a specific disease? Please bring us all the Ebola vaccines; if you refuse to bring [them] to us, how should we protect ourselves? Why is Ebola only in these two provinces and not others? Why is Ebola returning here when we are washing our hands?
<b>Vaccine</b> Questions about vaccine strategy.	If someone is vaccinated, can they no longer be infected? Can a vaccinated person still catch the Ebola disease? Why was there a major modification to the vaccine? Is this vaccine the real one? Is it possible to give the vaccine to those who were once denied it? Why don't you want to come and vaccinate us as fast as possible? Why do people keep dying when you're giving people the vaccine for [their] protection? Can someone who is vaccinated be vaccinated for a second time? Isn't the vaccine a way to kill us? When someone is vaccinated can his eyes go bad, or his body?
<b>Response processes</b> Questions around coordination, free case, and security.	Why don't you want to bring things for us to protect ourselves? Why don't you want to respond to our requests for handwashing stations? Why, here in our area, don't you raise awareness every day? What must we do for the outbreak to end? You, the responders, for how long will you stay here? We only see the Red Cross team doing the follow-up for cases of contact and visitors, why not the other people who work with the response? Why don't the responders want to put up barriers around where the Ebola is?
<b>Diagnosis, treatment and prevention</b> Questions about IPC measures and their functionality.	Are there any new medications that have been brought in to treat Ebola? What kind of disease is Ebola that has no cure? There are other places where there is no free medication so if a person gets a fever, are they left to die? You take a patient away in your ambulance, but after you take them away the victims die, why is that? Does it mean that there is no treatment for Ebola?
<b>ETC</b> Questions about diagnosis, treatment and triage and safety procedures	Why do you refuse to move the ETC to where the disease is found? Why did you move the ETC from Makeke? Is there good treatment for Ebola at the ETC? You told us that if we go to the ETC we will be cured, why do we continue to die at the ETC? Why is it that when a child is brought to the hospital and he or she has measles, we're asked to take them to the ETC?
<b>Transmission</b> Inconsistency in messages, questions about pathways.	If someone is cured of Ebola, can they no longer catch Ebola? Can people who have survived Ebola get sick with it again?
<b>Other questions</b> Questions about security, political issues, other social services and wider effects on economy/social life.	Why do the healthcare people want to get rich off the blood of others while they know the truth about Ebola? Why do you prevent us from eating meat, when the meat of mice is a medicine for children? Why not bring us water during the this dry season? What resistance is there to Ebola disease? Why did the Minister of Health resign? What do you want from the community through this Ebola epidemic? How can we protect ourselves from Ebola when we use public transport? How can you explain a victim's family getting rich after their death?

## Community suggestions

Suggestions made by communities during feedback sessions 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 June and August 2019 (rank 1 being the most frequently raised theme). A total of 28,776 comments were categorised as requests or suggestions. The most frequently cited suggestion involved expanding or modifying the vaccination programme. This was also the most frequent suggestion in the February-May 2019 reporting period.

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

	<b>June</b> 7,264 codings	<b>July</b> 10,700 codings	<b>August</b> 10,812 codings
	Beni, Bunia, Goma, Karisimbi, Komanda, Mabalako, Mandima, Nyiragongo, Oicha	Beni, Bunia, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mandima, Musienene, Nyiragongo, Oicha, Rwampara	Beni, Butembo, Goma, Karisimbi, Katwa, Komanda, Mabalako, Mambasa, Mandima, Nyiragongo, Oicha, Rwampara
<b>Rank 1</b>	Expand or modify vaccination programme	Expand or modify vaccination programme	Encourage handwashing
<b>Rank 2</b>	Encourage handwashing	Encourage handwashing	Need for other materials
<b>Rank 3</b>	Need for other materials	Need for other materials	Expand or modify vaccination programme
<b>Rank 4</b>	Response process suggestions	Response process suggestions	Response process suggestions
<b>Rank 5</b>	Improve health care	Improve health care	Improve health care

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) in the June-August 2019 period. Similarly to the last reporting period, suggestions mostly centred around expanding the vaccination programme, encouraging handwashing, improving healthcare and strengthening elements of the responses process. Expanding the vaccination programme is a key suggestion that communities continue to make and increased in frequency since the February to May 2019 reporting period so that it was again the most common suggestion in June and July 2019. The need for other materials, including requests for gloves, boots, chlorine and other protective equipment was also dominant theme. It was also notable that there were fewer comments (questions and suggestions) around burials in the IFRC community feedback during this period, continuing a downward trend in the data since late 2018. The closure of Makeke ETC in Mandima health zone led to multiple questions. Community suggestions were also collected by FHI-360, mostly around safe and dignified burials, in Musienene, Vuhovi, Butembo and Katwa health districts: One consistent piece of feedback was the request to engage with local community leaders who can work with youth in the communities (who might otherwise resist response activities).

<b>Expand or modify vaccination programme</b>	Please bring us the vaccine so we don't get infected; we don't need to lose our lives and our families. Why does this disease go on, is it because you only vaccinate some people? Protect us against Ebola virus disease; bring us the vaccine, please, we need it. Keep researching products to kill the Ebola virus; if it is the vaccine that will kill the virus, [then] bring us this vaccine. We know that the vaccine is good, but we are rather afraid of the soldiers who are escorting you. Many people ask for the vaccine; you have to bring the vaccine to each household, just like the other vaccines that we get. We ask you bring us the vaccine that won't kill us, for it to be the one that will protect us against Ebola virus disease.
<b>Encourage hand washing</b> Requests for handwashing stations and water.	Bring handwashing stations to every plot. We always ask for handwashing stations. Help us to have handwashing stations. Bring us some handwashing stations to make it easier for us to clean up. Bring us handwashing stations for proper hygiene.
<b>Need for other materials</b> Requests for gloves, boots, chlorine and other protective equipment.	Bring us the protection tools against Ebola. Each plot needs the necessary equipment: we need gloves for our protection and we need disinfectant in each household; we need chlorine for good protection. Bring us boots like the nurses have. You need to distribute rice to everyone, not just to the cases of contacts being monitored. Help us all and put up barriers everywhere so that the disease can end.
<b>Response process suggestions</b>	Let us protect ourselves against the Ebola virus disease whilst you keep looking for products to kill the outbreak of this Ebola virus disease. We need the outbreak to end, if you aren't here to kill us, then do everything possible to eliminate this disease soon. We want this disease to end and not remain at the root of fraud in our country. We need peace and the end of this disease. Do everything you can to eliminate your so-called Ebola disease because we are preparing a war for you; beware, leave in good time; everyone who works on the response must be careful.
<b>Improve burials</b> Specific requests around burials	When there is a death you should hurry up with the burial ceremony because we have discovered your secret of letting people be contaminated. The SDB teams in Vuhovi are not sufficient in relation to the number villages to be covered and the roads are not accessible for vehicles. The SDB teams have to walk on foot to reach the family of the deceased. We ask FHI 360 to set up SDB teams in Musenda, Kibwe, Bunyuka, Kasitu and Isonga so that the existing teams could be strengthened. Grave diggers from Kitatumba Cemetery asked for the involvement of community leaders to sensitise young people on Ebola so that they may stop disturbing, bothering and attacking SDB teams.
<b>Improve health care</b> ETC placement and closure, effective treatments, free healthcare	The community says that the ETC must be moved to where the disease is spreading. Continue to research products that can kill Ebola virus. You must also send the medication to places where there is no free medication. Many people from different places come for care to Makeke, we are afraid of being reinfected again, they must be treated back in their home towns. Bring us free care and come renovate your ETC. Bring us real medications.

## Key findings

### Awareness of Ebola:

There continues to be a high level of awareness about Ebola across the region. A large-scale study by the Harvard Humanitarian Initiative (HHI) in August 2019 found that 93% of respondents had heard of Ebola in North Kivu (n=2,267), 69% in South Kivu (n=2,316) and 49% (n=1,156) in Ituri Provinces. Awareness in the cities of Goma (99%), Bukavu (99%), Beni (96%) and Butembo (95%) were much higher than in the cities of Bunia (37%) and d'Uvira (76%). A study by the Cellule Analyse Science Sociale (CASS; the Social Sciences Analysis Cell, under the Strategic Commission of Ministry of Health and including UNICEF, WHO, CDC, Translators Without Borders and IFRC) with women from Beni (n=398, July 2019) found 100% were aware of Ebola, and similar levels of awareness (95% and 100%) were found in Goma (August 2019) by Oxfam (n=432) and CASS (n=84 healthcare workers). Community-level information exchange about Ebola was also found to be widespread: 77% of respondents in the CASS study in Beni (n=398, July 2019) had spoken about or heard people speak about Ebola in the last day; a separate CASS study (June 2019) found 80% of respondents in Butembo (n=198) and 49% in Katwa (n=226) had spoken about Ebola within the last week. The HHI survey in August 2019 indicated that Ebola was discussed daily or at least 2-6 times per week in North Kivu (78%), South Kivu (57%) and Ituri (42%), with much higher percentages found in Beni (95%), Butembo city (88%) and Goma (89%); but less in Mambasa (64%) and Mwenga (16%) where cases only started to emerge in July/August. The most common sources of information across North Kivu included: friends or family (91%), community radio (66%), health professionals (63%), religious leaders (61%) and national radio (34%). Survey data from CASS also suggested that radio was by far the most common source of information about Ebola in Bunia (88%), Butembo/Katwa (85%) and Beni (72%), with much higher exposure to information from health staff, community sensitisers, RECOs, family members and response staff in Butembo, Katwa and Beni in comparison to Bunia. In the HHI survey, however, only 30% of respondents in North Kivu, 22% in Ituri and 6% in South Kivu provinces felt that the information they had received about Ebola was sufficient. Qualitative studies from Mandima (CASS, June 2019) and the conflict scan by Search for Common Ground in Butembo (June 2019) found that confidence in information was strongly associated with 'knowing the source' and that local leaders, RECOs and informal leaders (motorcycle taxis, traditional healers, religious leaders) and friends and family were well respected in this regard. Interestingly, the CASS surveys found a larger percentage of respondents in Beni (60%) and Butembo (46%) in comparison to Katwa (22%) and Bunia (5%) who mentioned WhatsApp as a source of information, particularly among young people. While only 16% mentioned the internet and social media (Facebook and WhatsApp) in the HHI survey (n=5,739), this figure was much higher in the urban centres of Goma (52%), Butembo (48%), Bukavu (47%), Beni (40%) and Bunia (40%). Media monitoring by Novetta (June-August 2019) found that while critical voices in more mainstream media had significantly decreased compared to earlier reporting periods, community radio stations and local WhatsApp channels remained highly active in amplifying misinformation about Ebola, including claims that response teams were deliberately spreading the virus (including in Beni city) as part of the 'Ebola business'. Doubts about the 'true existence' of Ebola and questions around the origins and persistence of the epidemic continue to be reported across the community feedback (Oxfam, June-July 2019). The HHI survey in August found that 24% of respondents across North Kivu, South Kivu and Ituri provinces believed that Ebola was not real; 31% reported that the Ebola crisis had been invented by authorities for money; and 33% that it was invented to destabilise the region. A separate survey by CASS (June 2019) found that while 93% of respondents in Katwa (n=226) and 85% Butembo (n=198) believed the virus was real, only 50% and 62% believed the epidemic itself was real (with more men (53%, n=264) than women (31%, n=160) expressing disbelief). A conflict scan by Search for Common Ground in Butembo (June 2019) estimated that only about one-third of respondents believed Ebola was a 'normal disease', with most reporting that the epidemic was caused by hidden political and economic motivations. CASS data from Beni (June 2019, n=398 women) suggested a much higher level of trust

that the epidemic is real (96%), although the subsequent resurgence of Ebola in the city has led to significant levels of distrust, anger and a resurfacing of various rumors (Novetta, July-August).

### Knowledge of Ebola:

The HHI survey of August 2019 (n=5,739) found that 39% of respondents in North Kivu, 43% in Ituri and 79% in South Kivu provinces reported a 'very bad' or 'bad' knowledge of Ebola. When disaggregated by place, percentages were much less, with 8% of respondents in Goma and 9% in Beni city reporting 'very bad' or 'bad' knowledge, although worryingly 34% reported this in Butembo city and 89% in Mwenga. Most studies indicate that people have a relatively high(er) knowledge of Ebola symptoms in hotspot areas. A CASS survey in Beni (n=398, June-July 2019) found that over 85% of respondents described headache, vomiting, fever, bleeding and diarrhoea as key symptoms. A common sentiment across the various qualitative studies was that 'all fevers' are now suspected to be Ebola. Fever was the most commonly reported symptom in the HHI August data, as reported by 63% of all respondents (73% in North Kivu, 51% in South Kivu and 60% in Ituri province). According to CASS data, 93% of respondents in Beni (n=398, June-July 2019), and 81% of respondents in Butembo/Katwa (n=424, June 2019) reported hemorrhaging/bleeding to be a common symptom of Ebola. Oxfam data indicated that 73% of respondents in Goma (n=432, August 2019) also reported this. Both CASS and HHI surveys repeatedly show that muscle pain, abdominal pain and intensive fatigue are not seen as common Ebola symptoms.

Multiple studies report the majority of respondents identify physical contact with the bodily fluids of a sick person to be a dominant route of transmission. Less mention sexual transmission. Across HHI's August survey (n=5,739), the most commonly reported ways to contract Ebola were: touching sick people (63%); touching dead people (56%); handling or eating wild animals/bushmeat (46%); touching something that a sick person (with Ebola) had touched (43%); and being in contact with the blood, urine, sweat or other body fluid of a person sick with Ebola (27%). By comparison, these percentages rose approximately 20-30% in the cities of Beni and Butembo (when disaggregated by location). The conflict scan conducted by Search for Common Ground in Butembo/Katwa (June 2019) found that understandings of Ebola transmission often involved some level of misinformation including that it was spread in the air, through simple greetings, and the consumption of infected meat, and that it continued to be associated, by some, with spiritual illness (that can only be cured by prayer) or poisoning (also reported in under studies, e.g., by CASS, May 2019; and Bethesda, July 2019, "For me Ebola does not exist...I think [my niece] was poisoned, but after her death, they told us that she had Ebola but I don't believe it").

Data from the HHI survey in August (n=5,739) found that 82% of respondents across the region associated Ebola with death. A qualitative study in Mangina by CASS (July 2019) suggested that most participants believed Ebola was a dangerous disease that kills and that they were at 'high risk' of contracting the virus, whilst a study in Goma by Oxfam (n=432, August 2019) found that 92% of respondents thought Ebola was a 'very serious' or 'serious disease'. These and other studies indicate a widespread perception that women and children are at higher risk: 75% of women in the CASS study in Beni (n=398, July 2019) believed that they are more at risk of Ebola because they had not received the vaccine (100%) and because of their role in the preparation of corpses (94%).

CASS studies found that 95% of respondents in Beni (n=398, June-July 2019), 77% in Butembo/Katwa (n=424, June 2019) and 35% in Bunia (n=397, July 2019) believed the virus could spread 'anywhere'. Respondents in Katwa (70%) and Beni (62%) were more likely to identify health centres as particular places of transmission in comparison to Bunia (17%) and Butembo (32%) but respondents across the studies also mentioned markets, transport centres and. CASS studies (June-August 2019) and Oxfam community feedback data (June-July 2019) also highlighted the persistent perception that response teams were a source of Ebola transmission. Nonetheless, most respondents in the CASS surveys confirmed that Ebola could be controlled, although greater emphasis was placed

on basic hygiene as the key control mechanism rather than the need to change other high-risk behaviours. Statements such as "Cases have increased because...the majority do not wash their hands before they eat" and "...[Ebola spreads because people] do not respect the hygiene rules in the market" were common (CASS, Beni, July 2019). Asked about the best ways to control Ebola, respondents in CASS surveys (June-July) in Butembo (n=226), Katwa (n=198), Bunia (n=397) and Beni (n=398) most frequently mentioned vaccination, safe and dignified burials, decontamination and going to an ETC.

'What is the best method to control Ebola?'	CASS surveys (June-July 2019)			
	Beni n=396	Butembo n=226	Katwa n=198	Bunia n=397
Vaccination	56%	59%	59%	59%
Safe and dignified burials	60%	33%	62%	15%
Decontamination	60%	33%	47%	<10%
Going to the ETC	45%	38%	44%	13%
Isolation	39%	22%	40%	12%

The HHI survey (n=5,739, August 2019) found that 33% of respondents across North and South Kivu and Ituri provinces knew how to report a suspected Ebola case (66% in Goma; 61% in Beni city; 67% in Butembo city; 68% in Nyiragongo; but only 25% in Mambasa where most cases have emerged since mid-September). People still have many questions about the origins of the virus and "who is behind it" and suggest that clarifying such questions would help control the outbreak. Qualitative research in Beni (CASS, July 2019) found that many people believed the virus had "returned to Beni" because it was a lucrative business: "Yes, [Ebola] has increased here, because the majority of people love money, and they have found work in the response and want Ebola to continue."

### Knowledge of Ebola among health workers:

Nosocomial transmission and the infection of health workers continue to be of great concern.<sup>9</sup> CASS surveys with health workers (June-August 2019) showed that 100% in Beni (n=46), 100% in Bunia (n=80) and 89% in Butembo/Katwa (n=59) believed that the Ebola virus was real (that it is not a "made-up disease"), yet 45% in Butembo and Katwa did not believe that the Ebola epidemic was real (that many cases are not "really" Ebola or that Ebola was being spread on purpose). In comparison, 0% in Beni and 20% in Bunia reported this. Knowledge of Ebola symptoms (headache, fever, vomiting, abdominal pain, intense fatigue, and diarrhea) were mentioned by more than 80% of health staff in Beni and 90% in Bunia. Health workers (including both private and public) from Beni and Bunia

Self reported care practices in response to a suspected Ebola case	CASS surveys (June-July 2019)				
	Beni n=46	Butembo n=41	Katwa n=18	Bunia n=80	Goma n=84
Isolate the patient	83%	50%	8%	80%	17%
Call the Ebola hotline	64%	0%	18%	59%	69%
Send them to the ETC	51%	17%	15%	30%	N/A
Call the RECO	21%	17%	44%	5%	N/A
Refer to another health clinic	11%	0%	13%	0%	7%

appeared more prepared to handle suspected Ebola cases compared to those in Butembo, Katwa, and Goma.

These differences are aligned with health workers' exposure to Ebola training. According to CASS surveys, 99% of health staff participants in Bunia and 98% in Beni reported having received training, but only 76% in Goma and Katwa and 59% in Butembo. Trainings focused on IPC, symptoms, triage and how to disseminate information to patients, with little information on safe and dignified burials (SDBs) or vaccination. Trainings in Beni, Butembo and Katwa were more frequently in an office or hotel (58%) rather than in a health structure (35%), which limited practical hands-on-learning and demonstrations. Compared with 60% of health worker participants in Beni and 59% in Butembo, only 41% in Katwa agreed that they were sufficiently engaged by the Ebola response, with many reporting a lack of involvement specifically through private facilities. Across Beni, Katwa and Butembo, 60% of health workers felt at high risk of Ebola. Healthcare workers continue to be accused of spreading Ebola, and 65% of health workers surveyed in Bunia, 51% in Beni, Butembo and Katwa and 35% in Goma indicated their perception of a general reduction in confidence in medical professionals. Of the health staff surveyed by CASS in Butembo and Katwa, nearly half felt unable to speak about Ebola to patients or community members although only 9% in Bunia and 6% in Beni reported this (i.e., 91% in Bunia and 96% in Beni felt able to speak about Ebola). Community tensions have been exasperated during this reporting period by various healthcare worker strikes (due to months of non-payment) and demands for hazard pay circulating on local media in Butembo (Novetta, June).

### Prevention behaviours:

In the cross-provincial HHI survey (n=5,739, August 2019), self-reported behaviour change was notably higher in North Kivu and Ituri than in South Kivu. Across the survey, 43% of respondents confirmed they washed their hands more frequently since the Ebola epidemic began (59% in North Kivu, 47% in Ituri, 23% in South Kivu). Other prevention behaviors focused on social distancing: 39% reported to avoid the body of someone who has recently died of Ebola (61% in North Kivu, 31% in Ituri, 16% in South Kivu); 37% avoided contact with someone who they believed has Ebola (60% in North Kivu, 32% in Ituri, 12% in South Kivu); 23% reduced physical interactions with others (31% in North Kivu, 21% in Ituri, 13% in South Kivu); 31% avoided contact with people suspected to have visited an Ebola affected area (43% in North Kivu, 34% in Ituri, 16% in South Kivu); 28% avoided contact with people who had contact with someone infected with Ebola (37% in North Kivu, 31% in Ituri, 15% in South Kivu), and 18% reduced physical interaction with relatives (20% in North Kivu, 23% in Ituri, 12% in South Kivu).

CASS surveys in Butembo/Katwa (n=424, June 2019) and Beni (n=398, July 2019) found that 83% and 75% of respondents felt capable of protecting themselves from Ebola. The data suggest that knowledge of prevention, as well as self-reported behaviour changes, continues to focus on basic hygiene such as hand washing with soap, chlorine and/or water (also reflected in Oxfam community feedback data in June). Analyses by CASS has related this to a lack of detailed understanding about the high-risk transmission routes (which receive limited attention within communities), and the notion that Ebola can be transmitted "everywhere" (see above). Local communities in Butembo and Katwa repeatedly highlight the gap in access to improved water, hygiene and sanitation (Oxfam June-July; Novetta, June-August). A mixed methods study on the perceptions and use of IPC-WASH kits distributed to houses around Ebola cases in Katwa and Butembo (CASS, n=103 houses, June 2019) reported that whilst 88% of those who received an IPC-WASH kit claimed it had protected them against Ebola, 41% also reported that the selective distribution had created tensions in their community.

Other data indicators that a number of pastors continue to claim Ebola does not exist and that "*it can be healed in the name of Jesus*" through prayer and "*hand-laying*". This has been identified by some as a risky practice that may contribute to spreading the virus (Novetta, July). In late August, teachers were reported to be implementing prevention behaviours in schools as part of their preparation for the new academic year (Novetta, August).

### Care-seeking and home care:

A survey of women conducted by CASS across 12 health areas in Beni (n=398, July 2019) found that 85% of respondents confirmed the time it would take them to seek care if they had malaria-like symptoms had not changed since the epidemic began. Asked what they would do should their child have a fever for two days, 57% reported that they would treat them at home for the first 48 hours. Other community studies from Butembo/Katwa (CASS, n=424, June 2019) and Bunia (CASS, n=397, July 2019) found that high fever, diarrhoea and vomiting were the most commonly mentioned symptoms that would motivate parents to seek care for their under-5 children at a health facility. Pain, medium fevers and intensive fatigue were far less commonly reported and were not as widely recognised as Ebola symptoms. Stories from families of Ebola victims, collected by Bethesda Counseling Center (June-July 2019), highlight the complexity of care seeking, particularly when Ebola symptoms mimic malaria and other more common conditions. (In one reported case, a nurse encouraged a male patient initially diagnosed with malaria and then poisoning, to leave a hospital to seek herbal treatment and he subsequently died from Ebola).

Qualitative research in Beni, Mandima and Mabalako (CASS, April 2019) suggested that pathways for care continue to be diverse, with decision-making influenced by distance to clinic, levels of trust and credibility, perceptions of the quality of care and financial barriers. Respondents to CASS surveys in Butembo/Katwa (n=424, June 2019) and Bunia (n=397, July 2019) were asked what they would do if they suspected a family member had Ebola: 26% in Butembo/Katwa and 65% in Bunia reported that they would call a doctor/nurses to come to the house; 31% and 37% would go to health facility; 41% and 25% would call the Ebola hotline; 18% and 31% would go to the pharmacy; and 9% and 33% would see a traditional healer. By contrast, in a study conducted in Beni (CASS, n=398, June-July 2019) 82% of participants reported they would take a sick family member to a Formation Sanitaire (FOSA) with triage, while only 6% would visit a pharmacy, 7% traditional healers and 5% would stay home.

In the cross-provincial HHI survey (n=5,739, August 2019), 59% of respondents reported they would go to a hospital if they suspected they or a family member had Ebola (61% in North Kivu, 48% in Ituri, 64% in South Kivu), and 27% reported they would go to the health centre (28% in North Kivu, 35% in Ituri, 21% in South Kivu). Across the three provinces, 3% suggested that they would refuse care (4% in North Kivu, 3% in Ituri and 1% in South Kivu). Interestingly, in Mambasa (which saw a rise in cases in June<sup>10</sup>), 16% of respondents said they would present to a community health worker first. In Beni, 88% would go to a hospital and 5% to a health centre. No respondents in Beni said that they would go to a community health worker first, but 4% suggested they would refuse care if they suspected Ebola. In contrast, qualitative data from Beni, and elsewhere, continues to indicate support and preference for home care: "*People prefer to be treated at home for fear of being sent to ETC...[there are] too many deaths of Ebola people in hospitals*";

"People prefer self-medication because they are afraid of the FOSA and know that they will be taken directly to the ETC" (CASS, June 2019). Community surveys by CASS found that 70% in Katwa (n=226, June 2019), 55% in Beni (n=398, June-July 2019) and 38% in Butembo (n=198, June 2019) reported that they had "more fear" about seeking care from health facilities since the Ebola epidemic began, and that 43% in Katwa, 38% in Beni and 19% in Butembo feared being sent directly to a ETC: "Now everything is Ebola...the staff do not take care of the patients quickly, they send [them] to the ETC; staff [have] become enemies of the patients" (CASS, Beni, July). A qualitative study by CASS with community members, local leaders, health agents, community volunteers and response staff across five health zones in Beni, Mandima and Mabalako (April 2019) found that the most important motivator for rapid presentation of suspected Ebola cases was associated with increased chances of survival, and that greater exposure to survivors and the circulation of their experiences could help improve and encourage positive health seeking behaviour.

### Engagement with public and private health facilities:

Patient numbers at health facilities across the region appear to have increased since the outbreak began: 43% of health staff included in a study by CASS in Beni, Butembo and Katwa (n=105, June 2019) reported more patients visiting their facilities, and largely attributed this to the free care policy. A population-based CASS survey (June 2019) found that 58% of participants in Katwa (n=226) and 53% in Butembo (n=198) believed people visited clinics more often since Ebola, and a study amongst women in Beni (CASS, n=398, June 2019) found that 80% reported having confidence in the free care policy, although as noted in the Oxfam community feedback (July) some also felt that the increased number of patients had led to poorer quality care. Community members appeared confused by the suspension of free health care in parts of North Kivu, and noted the lack of transparency in the policy, claiming funding was not reaching communities and that "Millions and millions of dollars" were being kept by corrupt response teams (Novetta, August; Oxfam, July). Risk of Ebola infection at health facilities due to inadequate IPC was also widely discussed in the community feedback, with stories of nosocomial transmission due to sub-standard maternal medical care and medical neglect due to health worker strikes being highlighted across data sets (e.g., Bethesda Counseling Center, June-July 2019). Indeed, local media cited the lack of medical staff due to payment strikes as a reason why rates of routine child vaccination were reportedly falling and why other common diseases (like malaria) were increasing across the region (Novetta, June-July 2019).

Data suggests that IPC practices by health staff in Beni were stronger than those in Butembo and Katwa. In a CASS study of knowledge, perceptions, attitudes and practices of Ebola risk amongst health staff (n=105 health staff in public and private health facilities in Beni (n=46) Butembo (n=41) and Katwa (n=18), June 2019), 79% of health staff who participated in Beni reported having an IPC protocol in place for a suspected Ebola case compared to only 16% in Butembo/Katwa. In a similar study with health workers in Bunia and Rwampara in July 2019 (n=80 from 32 health structures across 19 health zones), 44% of respondents confirmed they had an IPC protocol in place. Whilst 87% of health care respondents in Beni (June 2019) and 55% in Bunia (July 2019) reported that the health structure where they worked had the necessary materials to stop Ebola transmission, only 28% of health structures included in a CASS survey in Goma (n=84 public, private and traditional health structures across three health zones) reported to have an adequate level of IPC to prevent nosocomial transmission. Respondents highlighted a lack of beds, gloves and other IPC materials, permanent water supplies and latrines, as well as limited triage and no isolation units. A community survey in Goma and Nyiragongo health zones by Oxfam (n=432, August 2019) found that 95% of respondents (who provided recommendations, n=167) prioritised access to water as the top recommendation to improve health facilities, and 90% of these believed that improving WASH would increase patient attendance numbers.

94% of health workers in Beni (CASS, n=46, June 2019) and 91% in Bunia (CASS, n=80, July 2019) confirmed that they felt capable of communicating about Ebola with their patients or community, whilst only 51% in Katwa (CASS, n=18, June 2019) and 55% in Butembo (CASS, n=41, June 2019) reported this. Health staff from Butembo and Katwa were far less likely than staff from Beni to describe the need to quickly isolate a patient suspected of Ebola and to call the Ebola hotline (CASS, June 2019).

### Engagement with tradi-practitioners:

The CASS survey of health staff (n=105, June 2019) found that 72% of health staff in Beni but only 11% in Butembo/Katwa reported that tradi-practitioners were involved in the Ebola response, whereas 55% in Beni and 68% in Butembo/Katwa reported the involvement of pharmacies. The perceptions of tradi-practitioners by WASH/IPC staff were mixed with some believing they were "charlatans" whilst others conveyed more positive relationships and advocated for them to be better integrated in the response. Most health workers suggested that tradi-practitioners were held in high confidence community members by who trusted them. Qualitative research in Mandina (CASS, June 2019) indicated that whilst community members preferred to seek care at a modern facility for Ebola (as well as malaria), they preferred care from tradi-practitioners for conditions including fever, poisoning, epilepsy and mental illness. The August 2019 CASS study on implications of tradi-practitioners across nine health zones in Beni, Mandima and Mabalako that included focus group discussions and interviews with tradi-practitioners, their clients, and members of the WASH/IPC commission, identified multiple types of traditional healers operating across the region (herbalists, magicians, marabouts, rebouteurs and feticheurs). All 21 tradi-practitioners interviewed in the study knew of the risk of acquiring Ebola because of their work and 20 had received the Ebola vaccine. Six emphasised that they lacked protective gear and only one (of the 51 tradi-practitioners included in interviews and focus groups) confirmed that they had received a WASH kit to protect themselves.

### Perceptions of ETCs and Ebola treatment

In two CASS surveys in Beni (n=398, July 2019) and Bunia (n=397, July 2019), 95% of respondents had heard about ETCs. In the HHI survey (n=5,739, August 2019), 71% of respondents in North Kivu, 42% in Ituri and 29% in South Kivu reported to have received information on where to go for Ebola care within the week prior to the survey. Data from surveys carried out by Novetta between June and August 2019 indicated that 57% of respondents were in support of the ETC in Beni (n=200) and 65% in Butembo (n=350). Community members expressed their desire to "defend" ETCs from attack in Katwa (Novetta, June) and their gratitude for foreign medical workers and NGOs: "We have to bring MSF back, they know how to treat" (CASS, Beni, July 2019). Nevertheless, the perception of ETCs as "deathtraps" continues in the community feedback (as recorded by both the IFRC and Oxfam), media monitoring (Novetta), qualitative studies (CASS) and conflict scanning (Search for Common Ground). Issues raised continue to be related to organ trafficking, stealing blood, ethnic cleansing, differential access (the exclusion of people with certain blood types), and deliberate killings conducted by response staff. Community members continue to feel that local doctors and nurses have not been sufficiently

trained in Ebola management, and throughout the feedback data, multiple complaints are articulated related to long waiting times, delayed or incorrect test results, and the lack of information being provided to family members (particularly when a patient has died). Concerns about the provision of food at the ETCs continue to be raised and have also circulated on local social media (Novetta, June 2019).

Across the reporting period, data suggests that the separation of ETCs from the general health system alongside the militarisation of care structures, hastily erected temporary structures, the perception that ETCs are inappropriately located (too close or too far from communities) and the lack of locally hired staff continue contribute to misinformation and mistrust across the region (CASS, Oxfam, Novetta, Search for Common Ground). The August 2019 HHI survey concluded that only 53% of respondents across North Kivu, South Kivu and Ituri said it was “likely” or “very probable” that they would inform health authorities if they suspected they had Ebola, and that reluctance to report was associated with the belief that Ebola does not exist (40%), that there is no cure (25%), a reluctance to be separated from family (23%) and a general distrust in authorities (20%).

More positively, however, data from CASS surveys in Butembo/Katwa (n=424, June 2019) and Beni (n=398, July 2019), and from Oxfam’s survey in Goma (n=432, August 2019) found that 73% of community member participants in Butembo/Katwa, 69% in Beni and 57% in Goma believed that Ebola could be successfully treated. Search for Common Ground’s conflict scanning in Butembo (June 2019) also indicated that some community members believed that if a patient goes to an ETC as soon as they show signs of Ebola, it is guaranteed that they will be cured. However, in HHI’s cross-provincial survey (n=5,739, August 2019), only 43% of respondents in North Kivu, 22% in Ituri and 8% in South Kivu were aware of a treatment for Ebola. Although figures were higher in Beni (79%) and Butembo (59%), they remained low in Goma (38%) and Mambasa (32%). Across the survey, 81% of participants reported that “all” (33% of respondents) or “most” (48% of respondents) people who are infected with Ebola die. In Beni, 25% suggested that all die, and 70% that most people die; and in Butembo, 18% suggested all die, and 68% that most die. Data from Search for Common Ground (Butembo, June 2019) suggested that the perception there was “no treatment” for Ebola at the start of the epidemic continues to linger.

Media monitoring by Novetta (June-August 2019) suggested that while major regional and national media have pushed a positive narrative of the ETCs for months, local- and community-based media have been slower to report on positive outcomes from the treatment centers. The announcement in August 2019 that the REGN-EB3 and mAb114 experimental therapeutics contribute to high survival rates, particularly if administered early, drew support and praise in local media, specifically surrounding the role of Dr. Jean-Jacques Muyembe. However following the reports of an Ebola “cure”, people have now started to assert that Ebola should claim no further lives and that all Ebola patients should be cured (Novetta, August).

#### Knowledge and understanding about the Ebola vaccine:

At the time of publication (6 October 2019), 233,366 people at risk of Ebola had consented to and received the rVSV-ZEBOV-GP Ebola vaccine.<sup>11</sup> The vaccine has a strong level of community acceptance, and community demand to expand the vaccine programme and for large-scale community-wide vaccination continues to be emphasised (IFRC, Oxfam, Novetta). Community members continue to call for more detailed information about the vaccine – vaccines are one of the highest categories in the IFRC community feedback data. CASS survey data suggested that nearly all health staff and most community members that participated in surveys during the reporting period had heard about the Ebola vaccine. However, fewer community members believed that the vaccine actually protects people from Ebola. These findings were aligned with those from the HHI survey (n=5,739, August 2019), which showed that 75% of participants in North Kivu, 63% in Ituri and 45% in South Kivu had heard about an Ebola vaccine but that only 58%, 43% and 59% respectively thought that it actually protected against Ebola. In turn, this mirrored the percentage of respondents who reported that they would indeed accept the Ebola vaccine if it was available to them: 61% in North Kivu, 48% in Ituri and 70% in South Kivu. As Ebola continues to circulate, doubts about the efficacy of the vaccine continue to circulate, including ideas that the vaccine spreads Ebola, has expired and that response teams distribute both an effective and an ineffective vaccine (CASS, Oxfam, IFRC), “*The vaccine that they use in Beni is not [effective]. The good vaccine is not in supply anymore only the bad vaccine remains*” (Novetta, August). Data also suggested that hesitancy to vaccines in general remains an issue across the region and was most pronounced in Ituri Province.

Self-reported changes in perceptions of Ebola vaccination in Beni and Butembo, HHI surveys, Sept/Dec 2018 and May/August 2019

Self-reported changes in perceptions of Ebola vaccination	HHI surveys (2018-2019)							
	Beni city				Butembo city			
	Sept '18 n=481	Dec '18 n=302	May '19 n=600	Aug '19 n=309	Sept '18 n=480	Dec '18 n=300	May '19 n=599	Aug '19 n=384
Have you heard about the Ebola vaccine?	97%	89%	93%	93%	85%	99%	94%	95%
Does the vaccine protect against Ebola?	69%	82%	74%	68%	65%	53%	40%	60%
Would you accept the Ebola vaccine?	57%	70%	55%	65%	65%	38%	31%	58%

Material gathered by Search for Common Ground in Butembo (June 2019) highlighted unconfirmed rumours that some response staff still refuse to be vaccinated. In the CASS study with health staff in June 2019, participants were asked why health workers may not want to be vaccinated and suggested fear of side effects, fear that it is fatal, and fear that it is ineffective. Further insights into Ebola vaccine hesitancy were provided by the short surveys conducted by Novetta between June-August in Butembo (n=365) and Beni (n=202) where, apart from the limited availability of the vaccine (“*I have wanted to get vaccinated, but it is very difficult to get*”), other commonly cited reasons included: pregnancy status, religious beliefs, beliefs about it being a “poison” and spreading Ebola (“*as a way to exterminate the Nande people*”), concerns about it being “experimental”, and fears that it causes impotence, infertility and debilitating, long-lasting health side effects. Community feedback continues to highlight delays in vaccine administration to Ebola contacts, community tensions around the provision of food to Ebola contacts (seen as a “reward” for accepting the vaccine) and community complaints that response staff were are not always able to explain how the vaccine works and the rationale for ring vaccination. The experimental nature of the vaccine was seen to be particular problematic: “*I will never accept it...they treat us as laboratory mice....the response teams must stop killing us. Enough!*” (Novetta, July).

Confusion continues around the eligibility criteria for receiving the vaccine. A survey conducted by Oxfam in Goma and Nyiragongo health zones (n=432, August 2019) found that whilst 68% of participants had heard of the vaccine, only 40% had received information

about the circumstances in which someone may be eligible to receive it. Similarly, in a CASS survey with health workers, also in Goma (n=84, August 2019) less than half understood the eligibility criteria: 46% of respondents believed that “everyone” could be vaccinated; 38% confirmed health workers could be vaccinated; and 16% confirmed Ebola contacts could be vaccinated.

In an already highly politicised environment, the planned introduction of the Johnson & Johnson Ebola vaccine<sup>12</sup> has been accompanied by various community concerns and the recycling of mis-and dis-information previously expressed in relation to the Merck vaccine (Novetta, July-August). Little information is being shared about the second vaccine introduction on local radio or media channels, yet new questions have already arisen in the IFRC community feedback data such as “Why was there a major modification to the vaccine, is this new one the real one?” and “Can someone who is vaccinated be vaccinated for a second time?” This question is also concerning given the fact that the Johnson & Johnson vaccine is a prime-booster vaccine, with the second dose to be administered 56 days after the first. In addition, suspicions about the Johnson & Johnson vaccine have been related to the fact that it was earlier blocked by former Minister of Health Dr. Illunga (who resigned on 22 July 2019) and communities question whether this is a new way to spread Ebola, a new way to profit from the epidemic or is actually the “real” vaccine and that the “old one” is no longer effective.

### Burial practices:

Overall, the social and behavioral science data collected in the June-August 2019 suggests a moderate-to-high acceptance of safe and dignified burials (SDBs), including in previous hotspot areas.<sup>13</sup> A study by CASS (n=424, June 2019) found that 41% of community members in Butembo/Katwa had interacted with a SDB team. In the rapid KAP study with women in Beni in June-July 2019, CASS asked respondents what they would do if someone was suspected of dying from Ebola in their community: 44% of women said they would inform the Red Cross; 24% that they would inform local leaders; 21% that they would call the “green number” (i.e., the hotline/alert number); and 11% that they would do nothing. In the same study, only 14% of respondents claimed they would accept a non-family member burying an Ebola case, whilst in a related study by CASS with women in Bunia (n=397, July 2019), 52% reported they would agree to this. The cross-provincial HHI survey (n=5,739, August 2019) found that only 25% of respondents would accept medical staff dressing a dead body instead of a family member for a funeral (although this percentage increased to 85% in Beni and 51% in Goma, but only 37% in Butembo). Communities continue to voice concerns about burials conducted by SDB teams, specifically related to long delays (arriving late) and a lack of respect for various customary mourning practices. Qualitative research in Mandima found this to include not washing the body before burial; not braiding the hair of the deceased; and burying pregnant women and fetus’ together (CASS June 2019; Search for Common Ground June 2019; Oxfam July 2019). Media monitoring found multiple accounts in local media of resentment toward SDB teams, with claims that they were “aggressive” and would not communicate with grieving families: “We had many things to ask them, but they will not listen to us, only if we have more bodies to give them [will they speak to us]” (Novetta, July 2019). In the community feedback and various qualitative studies, community members continue to raise many questions about SDBs: why the burial protocol has to be followed for non-Ebola deaths; why names are not put on the graves of Ebola victims; why response teams are escorted by police; concerns about pre-digging graves (which reinforces the view that the response teams deliberately kill people); concerns about plastic body bags not degrading in the soil (and keeping the spirit of the deceased from the afterlife or being used to steal organs) (CASS June 2019; Search for Common Ground June 2019; Novetta June-July 2019). Reports on local media, including WhatsApp, have included a few accounts of youth groups breaking into morgues to try and steal the bodies of their relatives or friends, and then claiming that they have seen mutilated bodies (Novetta, June 2019). Fear and concerns about SDB continue: “These people come to kill us...dressed oddly in these protective suits, [they] bring Ebola into our neighborhood” (Novetta, June). However, there are also repeated calls for more material support to be given to local communities to carry out their own safe and dignified burials and Local youth leaders in Katwa asked that gloves, funeral bags and coffins be used to demonstrate to community members the SDB process before the teams arrive (CASS, June 2019).

### Survivors and psychosocial support:

Survivors have been seen to make an important contribution to gaining community trust in the Ebola response and presentation at ETCs (see above). However their increased visibility may also bring additional stigma and community fears about transmission from survivors, particularly through sexual transmission (Novetta, July-August 2019). The community-based survey by Oxfam in Goma (n=432, August 2019) found that 44% of respondents expressed fear about survivors, mostly due to concerns related to catching the virus through sex, saliva, blood or other bodily fluid. A survey by CASS (n=424, June 2019) found that 65% of respondents in Katwa (n=226) and 47% in Butembo (n=198) believed Ebola could be spread sexually, an issue also reflected in community feedback data (IFRC and Oxfam). In the August HHI survey (n=5,739), only 14% of total respondents believed that Ebola could be spread sexually, but this percentage increased to 45% in Goma, 33% in Butembo and 26% in Beni. Local media monitoring also noted heightened anxieties about the persistence of the virus in semen, “[Ebola] healings are very dangerous because their sperm carries the virus for 506 days and...the products they took to heal are sexual stimulants” (Novetta, August 2019). Similarly, in community suggestions collected by FHI-360 in Musiene health zone in August also included a focus on transmission from survivors: “Ebola patients who were healed must be put in quarantine since the virus can remain in certain bodily fluids for 500 days... If the EVD Response Coordination does not take care of people cured from Ebola, the community will manage these cases... Because we don’t want to see them in our community before the virus disappears in their body”.

Across studies that have engaged survivors, many reported that they are often stigmatised as soon as they are reintegrated back into their community, with some reportedly being avoided by their families (including spouses) and friends (Search for Common Ground June 2019; Bethesda July 2019; Novetta July 2019): “My husband loved me very much but after my illness, things changed. My husband has no confidence in me. When we eat together, he avoids using the same plate as me and seems to have no appetite like before. He left the bed” (Bethesda, Beni, June-July 2019). The 21 days monitoring period can contribute to fatigue and stigma, while the distribution of food kits and decontamination efforts have magnified community tensions in some areas: “I am now accused of corruption [since I have] received a gift from the response”, “The community and everyone around me has rejected me. It started the day my house was decontaminated” (CASS, May 2019). In their conflict scanning in Butembo, Search for Common Ground (June 2019) found that some survivors lacked essential information about how to navigate post-recovery health challenges and where to seek help. Yet other families have significantly benefited from on-going psychosocial work, including efforts addressing grief and memorialisation by Bethesda Counseling Center in Beni. In their feedback, communities regularly ask that such interventions be



scaled-up: “As survivors of Ebola, we want you to extend this programme to many other places, go around the towns and villages. There are so many people out there who need this support” (Bethesda, Beni, June-July 2019).

### Community perceptions of the response:

The data shows both increasing and decreasing levels of support for the Ebola response across the region, making it difficult to evaluate trends. Nonetheless, requests consistently focused on the need for greater localisation of the response and more community leadership in order to end the epidemic. This often emphasised increased involvement of local health staff, leaders (traditional communal chiefs, religious, women, youth), civil society organisations (including media and journalists) and community members (such as community health volunteers), who speak the local language and are known in local social networks (CASS June 2019; Search for Common Ground June 2019). Novetta’s analysis found that the most negative comments in local media focused on the international and NGO response, whilst more positive comments emphasised the work of local stakeholders (Novetta, July 2019).

Community-level data highlights repeated calls for resources to be given directly to community stakeholders to implement local solutions, and requests for more consultation and greater transparency and accountability. In June 2019, 68% of women included in the CASS study in Beni (n=398) reported that there were too few women integrated in the response, and in studies conducted in June 2019, CASS found that only 13% of respondents in Katwa (n=226) and 44% in Butembo (n=198) believed that “all layers” of society were involved in the Ebola response. Most community members do not understand the function of different interventions and some perceive the multitude of partners as a sign of a fragmented response with different organisations competing against each other for resources and control (Novetta June-August 2019, Oxfam June-July 2019). Still, a KAP survey with community members in Katwa to evaluate NGO activities related to Ebola prevention and control (n=196, June 2019) found that 40% of respondents had participated in at least one community meeting on Ebola, and most demonstrated high levels of acceptance in relation to Ebola control activities.

The socio-behavioural data for this reporting period also shows a diverse number of negative perceptions about response agents that act as barriers to building trust and mutual acceptance including claims of response teams exhibiting aggressive behavior and/or a sense of superiority and contempt; lengthy procedures and slow arrival times; and a perceived lack of decorum (e.g., wearing headphones when talking to people and wearing inappropriate clothing). The CASS KAP surveys in Butembo/Katwa (n=424, June 2019) and Beni (n=398, June 2019) found that over half of all respondents believed response staff did not have sufficient information to respond to community questions.

The idea that local politicians have been “bought” by the response continues to circulate widely, and gained traction in the local media after the resignation of the former DRC Minister of Health Dr. Oly Ilunga. Government claims that the epidemic will end within a specific timeframe (e.g., in three months, or by the end of the year) also reinforce the idea that response teams can control the epidemic and are deliberately spreading the virus for financial gain. These perceptions are further magnified as the response has increased the profits of some traders and businessmen (what has been termed the “Ebola Business Zone”, Search for Common Ground, June 2019), but has reduced the purchasing power of the average household. The unprecedented deployment of logistics and staff continues to reinforce the idea that the epidemic is manufactured for profit: “Ebola is a business. A simple epidemic has mobilised all these different actors but we wonder why cholera, measles and other diseases do not have nearly the same mobilisation like Ebola” (CASS, Beni, July 2019). Of all comments through IFRC community feedback mechanisms between 22 July and 16 August 2019, 5% (1,463 / 31,198 comments) related Ebola and the response to money and politics: “Ebola is an opportunity for some people to have money instead of curing the sick” and “Ebola is not real, you, the health promotion workers, are here to profit”. In total 12% of the comments asserted that Ebola does not exist but that it was made up for financial reasons: “Ebola is a fabrication of certain greedy people.” Communities continue to articulate urgent questions about the use of resources and the sustainability of health investments, with some asking that Ebola funds be used to rehabilitate medical facilities, laboratory and training institutes in the region and that resources be re-directed to invest in infrastructure including access to safe water, particularly for schools and health facilities (Search for Common Ground June 2019, Oxfam June-July 2019).

### Violence and insecurity:

Security issues remain a top community priority, often over and above Ebola. Novetta’s analysis suggests that local media coverage of the virus remains highly influenced by the security situation. When ADF (Allied Democratic Forces) and FARDC (Forces Armées de la République Démocratique du Congo) movements occur, Ebola coverage declines for the subsequent one to two weeks (Novetta, June-August 2019). Communities continue to express frustration, as they do not perceive the UN and MONUSCO to be effectively addressing the ongoing violence.

The escalation of violence since June in Beni (including an attack on city hall by an ISIS affiliate network of ADF militants in August 2019) was perceived by some community members to draw focus away from the outbreak as insecurity incidents continue to result in curtailing response activities (contact tracing, vaccination etc.) whilst other community members demand that resources be directed away from the Ebola response to bolster security operations. Some communities called for strengthening citizen armed defense groups and staged multiple “ville mort” to call attention to the rising death toll from ADF attacks (Novetta, June-August 2019). In late August, the Beni chapter of the Veranda Mutsanga and La Lucha (most prominent in Goma), both youth/social pressure groups, stopped their active support of the response in political protest and called for the interruption of community-based Ebola activities (Novetta, August 2019).

The violence and insecurity also continues to be a direct threat to healthcare workers and other Ebola response staff with recent attacks on the convey of the Minister of Health, looting of Ebola testing facilities and the burning of response vehicles (Novetta, June-July 2019). CASS surveys with health workers in Beni (N=46, June 2019) and Bunia (n=80, July 2019) found that half of all respondents feared being attacked by their community and around one third feared having their health facility attacked. Qualitative data from Butembo, Katwa and Mandima (CASS, May-July 2019) showed that health workers face repeated threats and accusations that they are “working for Ebola” and are paid by the response to refer patients to ETCs.

## Studies included in the synthesis brief

Organisations	Study description	Timeframe of data collection	Methods
Bethesda Counseling Center – Congo Initiative	Psychosocial intervention program	June – July 2019	25 recorded stories with Ebola survivor families in Kangaambi and Vingazi neighborhood in Beni
CASS	Study on the reasons for delays in therapeutic itineraries	April 2019	10 focus group discussions and 50 in-depth interviews with community members, local leaders, health agents, community volunteers and response staff. Research in 5 health zones in Beni (2), Mandima (1) and Mabalako (2).
CASS	Barriers and motivators of participation in listing and tracking of Ebola contacts	May 2019	9 focus group discussions and 34 interviews (contacts, RECO, investigators, non-contacts) in Butembo and Katwa.
CASS	KAP study in Butembo/Katwa	June 2019	A survey with 424 participants (264 men and 160 women) in Butembo and Katwa
CASS	Sociocultural context in Mangina	June 2019	56 focus group discussions and 35 individual interviews across 7 health zones in Mangina.
CASS	Knowledge, perceptions, attitudes and practices of Ebola risk among health staff in Beni, Butembo and Katwa	June 2019	A survey of 105 health staff across public and private health facilities in Beni (46), Butembo (41) and Katwa (18).
CASS	Rapid KAP study with women in Beni	June-July 2019	A survey with 398 women across 12 health areas in Beni.
CASS	Perceptions and use of IPC-WASH kits distributed to houses around Ebola cases	July 2019	A survey with 103 households in 4 health zones in Butembo and 8 in Katwa
CASS	Perceptions and possible causes of Ebola transmission in the “hot-zones” of Beni	July 2019	24 focus group discussions and 118 surveys in Butsili, Ngongolio and Kanzulnzuli health areas of Beni.
CASS	Community perceptions of the Ebola Treatment Center (ETC) in Kanyaruchinya (health zone of Nyiragongo).	July 2019	24 focus group discussions (192 participants) and 11 individual interviews in Kanyaruchinya (health zone of Nyiragongo).
CASS	KAP in Bunia	July 2019	A survey with 397 women across 15 health zones in Bunia and Rwampara
CASS	KAP in Bunia and Rwampara with health workers	July 2019	A survey with 80 respondents from 32 health structures across 19 health zones, including staff from private (43), public (15), traditional (21) and hospital (1) facilities.
CASS	Study on the implications of tradipractitioners (traditional healers)	August 2019	14 focus group discussions (8 with tradipractitioners, 6 with clients) and 27 individual interviews (14 with members of the WASH/IPC commissions and 13 with tradipractitioners) in 9 health zones in Beni (4), Mandima (3) and Mabalako (2).
CASS	KAP in Goma with health workers	August 2019	A survey with staff from 84 health structures (public, private and traditional) in the health zones of Goma (19), Karisimbi (45) and Nyiragongo (20)
FHI 360	Community feedback qualitative data	August 2019	20 focus group discussions in 5 health zones (Katwa, Butembo, Bunia, Nyakasanza, and Komanda) and 4 in-depth interviews with traditional leaders.
Harvard Humanitarian Initiative (HHI)	Large-scale survey	July – August 2019	A random sample of adults (n=5,739) from North Kivu (n=2,267), South Kivu (2,316), and Ituri (n=1,156).
IFRC	Online community feedback dashboard containing qualitative perception data.	June – August 2019	A total of 27,977 community feedback comments, 30,128 questions and 28,776 suggestions. Further information about the system and methodology can be accessed at: <a href="https://odihpn.org/magazine/bringing-community-perspectives-decision-makingebola-response-democratic-republic-congo/">https://odihpn.org/magazine/bringing-community-perspectives-decision-makingebola-response-democratic-republic-congo/</a>
Novetta	PALM Social Analytics	June – August 2019	Three surveys with randomly selected participants: Beni (n=200) Butembo/Katwa (n=350) Mangina (n=50). Monitored traditional media sample registered 19,000 quotes and 3,000 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, and using the Community Perception tracker (CPT).	June – July 2019	323 community feedback statements in Beni (117), Butembo (107), Katwa (67), Mandima/Mabalako (31), and Nyiragongo (1).
Oxfam	KAP study to evaluate NGO activities related to Ebola prevention and control	August 2019	A survey of 196 households across 4 health areas in Katwa.
Oxfam	KAP study in Goma and Nyiragongo health zones	August 2019	A survey of 432 households across 5 health zones in Goma and Nyiragongo health zones.
Search for Common Ground	Tupone Wote Pamoja (Conflict Scan, Butembo, North Kivu)	June 2019	24 focus group discussions and 27 key informant interviews in Butembo (Kayna, Katwa, Nyiragongo, Mbiza, Karisimbi and Rwanguba).

## References and notes

- <sup>1</sup> 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](https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14144/SSHAP_data_compilation_brief_November_2018_updated.pdf)
- 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\\_compilation\\_brief\\_2\\_March\\_2019.pdf?sequence=1&isAllowed=y](https://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/14389/SSHAP_data_compilation_brief_2_March_2019.pdf?sequence=1&isAllowed=y)
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- <sup>2</sup> WHO, External Situation Report 62, 8 October 2019.
- <sup>3</sup> WHO, External Situation Report 62, 8 October 2019.
- <sup>4</sup> WHO External Situation Report 46, 18 June 2019.
- <sup>5</sup> Further information about the system and methodology can be accessed at <https://odihpn.org/magazine/bringing-community-perspectives-decision-making-ebola-response-democratic-republic-congo/>
- <sup>6</sup> All ranks are based on frequency and were provided by CDC and IFRC.
- <sup>7</sup> There were 716 'other' questions in June. '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, although given the high workload, re-coding earlier data with new codes has not yet been possible. Statements coded as 'other' included: Why do the healthcare people want to get rich off the blood of others while they know the truth about Ebola? Why do you prevent us from eating meat, when that of mice is a medicine for children? Why not bring us water during the this dry season? What resistance is there to Ebola disease? Why doesn't the WHO want to do everything possible to eradicate this Ebola disease? Is it possible for the government to quarantine the affected areas? Why do they give money to anyone who brings an Ebola victim? The crowding in public transit, isn't that a way of exacerbating the Ebola infection? Why not close all barriers on the road between Butembo and Goma to avoid the spread of Ebola? If Ebola really exists, why not exterminate it? Why does the State seem to neglect the Ebola disease? Why do you leave the passages free during the night, can Ebola not be transmitted during the night? Why are the authorities calm and not intervening with regard to Ebola?
- <sup>8</sup> There were 854 'other' questions in August 2019. Questions coded as 'other' included: Why did the Minister of Health resign? What do you want from the community with this Ebola epidemic? How can we protect ourselves from Ebola when we use public transportation? How can you explain a victim's family getting rich after their death? How do you know that a person is affected with EVD when you haven't tested them? What are the recommended measures for public transit to fight the Ebola outbreak? How can we protect ourselves from EVD on a bus or motorcycle? After the epidemic will surveillance agents continue to work in the community? Has the Catholic church not yet sold their concession to the responders? Why do you wait for people to get sick before intervening? Can concentrated chlorine not cause certain diseases in the long run? Why not give the intercity drivers Thermoflash? Why are you abusing people with your Ebola disease? How do you explain [the fact] that Ebola devastated Beni-Butembo, there were no medicines there, but in Goma you find them right away? Why has Ebola become a drama in North Kivu province?
- <sup>9</sup> In the period 1 January 2019 to 23 September 2019, 14% (362/2,561) of EVD infections are thought to represent possible nosocomial infection (NI), according to the latest WHO situation report. During this same period, 105 healthcare worker (HCW) infections were reported, or 4% of total infections (106/2,561). Overall, Katwa HZ has reported the majority of HCW infections (32%, 34/106). WHO, External Situation Report 62, 8 October 2019.
- <sup>10</sup> During this period, a total of 129 confirmed cases were reported, with the majority coming from the health zones of Mambasa (25%, n=32 cases), Mandima (19%, n=25 cases), Kalunguta (17%, n=22 cases) and Beni (11%, n=14 cases). WHO External Situation Report 46, 18 June 2019.
- <sup>11</sup> Of those, 56,512 are contacts and 159, 882 contacts-of-contacts. The total number of vaccines includes 50,035 HCWs/FLWs. WHO, External Situation Report 62, 8 October 2019.
- <sup>12</sup> <https://www.who.int/news-room/detail/23-09-2019-second-ebola-vaccine-to-complement-ring-vaccination-given-green-light-in-drc>
- <sup>13</sup> According to the latest WHO situation report, during the week ending 7 October 2019, there were 525 SDB alerts recorded in 26 health zones. Of these, 429 (94%) were responded to successfully. Two health zones fell below the 70% success benchmark in Nyankunde and Masisi.

## 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](mailto:julietbedford@anthrologica.com)), Olivia Tulloch ([oliviattulloch@anthrologica.com](mailto:oliviattulloch@anthrologica.com)) and Santiago Ripoll ([s.ripoll@ids.ac.uk](mailto:s.ripoll@ids.ac.uk)).

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