Social science and behavioural data compilation, DRC Ebola outbreak, November 2018-February 2019

This rapid compilation of data analyses provides a 'stock-take' of social science and behavioural data related to the on-going outbreak of Ebola in North Kivu and Ituri provinces. Based on data gathered and analysed by organisations working in the Ebola response and in the region more broadly, it explores convergences and divergences between datasets and, when possible, differences by geographic area, demographic group, time period and other relevant variables. Data sources are listed at the end of the document.

The brief focuses on data generated between November 2018 and early February 2019, and also includes studies that were completed in October but only became available for analysis in November 2018. It builds on the previous SSHAP data compilation brief that synthesised social science and behavioural data generated in August-October 2018.

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Community feedback: themes and questions

Multiple organisations including the IFRC and the National Society of the Red Cross, Oxfam, UNICEF, WHO, IRC, other NGOs and local partners are compiling community feedback in North Kivu and Ituri provinces. According to organisations working on the ground, community feedback is analysed and discussed in Ministry of Health-led Ebola coordination structures to adjust and improve response actions.

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.[i] The table below presents the five themes most frequently identified in the community feedback gathered by Red Cross volunteers between November 2018 and 9 February 2019 (rank 1 being the most frequently raised theme).[ii] During the reporting period, 14,143 comments categorised as 'rumours', 'observations' or 'beliefs' were analysed. In the first months of the outbreak (Aug-Sept 2018), the majority of community feedback involved questions and concerns related to the causes of Ebola, the health system and response, and around Ebola being a scheme of the government. These themes have continued to dominate and most feedback from November 2018 to January 2019 focused on themes associated with Ebola being a scheme of the government. Critiques or observations of the health system were also dominant during the reporting period, and in February 2019 was the most frequently raised theme, particularly in Katwa and Butembo where many statements highlighted communities' perceptions of poor quality care and difficult interactions with response teams. This data indicates the key concerns of community members and must be taken into consideration by the response to further shape interventions, especially in areas including Katwa and Butembo that have recently experienced a surge in violence directed towards the response and response partners.

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

	November	December	January	9 February
	8,834 codings	10,482 codings	7,633 codings	2,440 codings
	Beni, Bunia, Butembo, Kasenyi, Katwa, Mabalak, Mandima, Masereka, Musienene, Oicha, Rwampara	Beni, Bunia, Butembo, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Oicha	Beni, Butembo, Katwa, Komanda, Mabalako, Mandima, Oicha	Beni, Butembo, Katwa, Mabalako, Masereka, Musienene, Oicha
Rank 1	Ebola is a scheme of the government or others	Ebola is a scheme of the government or others	Ebola is a scheme of the government or others	Critiques or observations of the health system
Rank 2	Other[iii]	Critiques or observations of the health system	Critiques or observations of the health system	Ebola is a scheme of the government or others
Rank 3	Critiques or observations of the health system	Ebola characteristics and consequences	Ebola is organised business	Ebola characteristics and consequences
Rank 4	Ebola is organised business	Ebola is organised business	Ebola characteristics and consequences	Ebola is organized business
Rank 5	Critiques or observations of the response	Ebola causes	Critiques or observations of the response	Critiques or observations of the response

[i] 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/

[ii] All ranks are based on frequency and were provided by CDC and IFRC.

[iii] 'Other' is a very heterogeneous group of comments that do not fit any of the codes in the current codebook being used by CDC to analyse the data. Comments in the 'other' category are regularly reviewed to identify new codes, although given the high workload, recoding previous data with new codes has not yet been possible. In November 2018, for example, statements coded as 'other' included appreciations of response workers and free healthcare; concerns around theft and political gains because of the response; discrimination regarding who is vaccinated; questions around signs and symptoms; concerns around response processes including the effect of chlorine intake on general health. Other comments expressed gratitude for family members who were praised for their participation in safe burial protocols; called for money to benefit local populations; and raised concerns around Ebola being a disease '*brought by white people*' and/or spread through food.

Questions asked by community members were also reported as part of the community feedback. During the reporting period, 10,916 questions from the Red Cross community feedback were collated and analysed by the IFRC and CDC. Questions about Ebola, its consequences, its treatment, and the vaccine continue to dominate. 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

	November 2018	December 2018	January 2019	9 February
	7,098 codings	8,306 codings	5,111 codings	1,791 codings
	Beni, Bunia, Butembo, Kasenyi, Katwa, Mabalak, Mandima, Masereka, Musienene, Oicha, Rwampara	Beni, Bunia, Butembo, Katwa, Komanda, Mabalako, Mandima, Masereka, Musienene, Oicha	Beni, Butembo, Katwa, Komanda, Mabalako, Mandima, Oicha	Beni, Butembo, Katwa, Mabalako, Masereka, Musienene, Oicha
Rank 1	Vaccine	Ebola and its consequences	Ebola and its consequences	Ebola and its consequences
Rank 2	Ebola and its consequences	Vaccine	Other[iv]	Diagnosis, treatment, ETC, health system
Rank 3	Diagnosis, treatment, ETC, health system	Diagnosis, treatment, ETC, health system	Response process	Vaccine
Rank 4	Other[v]	Other[vi]	Vaccine	Response process
Rank 5	Response process	Response process	Diagnosis, treatment, ETC, health system	Other[vii]

The following is a selection of questions repeatedly asked between November 2018 and February 2019 as documented in the community feedback gathered by the Red Cross and Oxfam and articulated during qualitative research conducted by the Communications Commission, IPC-WASH Commission, UNICEF, WHO, Oxfam, Medair, IRC, Mercy Corps.[1] Questions are clustered by key theme, not in order of frequency.

Vaccines Effectiveness, quality and consent	The vaccinated person, can they infect others? Does the vaccine kill female fertility? Why don't we vaccinate everyone? Is there no way to vaccinate the entire population? Why administer to the population a vaccine that's in the experimental phase? What will be the fate of the person who will refuse to be vaccinated? Is the vaccine for prevention or treatment? Why invest a lot of money to supply drugs to the hospitals when there isn't enough vaccine for everyone?
Response processes Ebola money, functionality and prioritisation	Who is paying the response teams? Is it true that the person who alerts gets $100? The toll-free numbers do not work, what to do? If we call during the night will you come? In case of emergency, if one doesn't have credit on a phone, how can someone call the hotline? Why do you come with many trucks to pick up a sick person? Why do they always come with the police/military? Why are you taking the suspects by force? Is it necessary to burn the house of a sick person with Ebola? Why so much focus on Ebola and not on the massacres or other diseases?
Diagnosis / treatment Outcomes, quality of care	Can you recover? Can you survive Ebola? How are they cared for in the ETC? Can patients eat? What medication do they take? Is it free? Is care good? Why are there not more ETCs? Why are local nurses and doctors not included in the care, why only the doctors from outside? Does free healthcare also include circumcision? When will free care stop?
Ebola and consequences Epidemiological developments, vulnerability	Where does the virus come from? Why did it happen here in North Kivu and nowhere else? Why, with all the means available for a response, are we not able to eradicate this epidemic? When will it end? Why are women much more affected than men? Can Ebola live on in the breasts of women who are cured of the Ebola virus? Why can't men sleep with women after recovering?
Ebola outcomes and protective behaviours	Can you get Ebola when you walk with bare feet? What animals should we avoid eating? Why haven't we ever seen the real signs of Ebola like bleeding as on the posters? Does it really exist? Can you show a picture of people who are dying of Ebola? Does the smoke of mattresses, clothes, sheets and other material from confirmed Ebola patients not contaminate surrounding communities with Ebola?
Burials Behaviour of burial teams, adapted burial practices	Can family members be present? Where does the body go before burying? Is it necessary to burn their possessions? Why do the SDB teams often bury only at night? Why does the SDB team dress themselves on site? Why don't the burial teams get ill? Why do response workers not cry? Why do you forcefully bury people, with policemen? Why don't we show the body of the deceased to their family members as is customary? Is it so that the cemeteries where Ebola bodies are buried won't contaminate others? What is the role of the body bag? Why are others doing burials without being protected like you told us?
Other questions Ebola business	Do you believe that the politicians are not in contact with the response teams? Why did Ebola appear just when elections are coming up? Has Ebola become a business here?

[iv] In November 2018, questions coded in the 'Other' category included the effectiveness of treatment in the ETCs; if deceased Ebola patients could "*contaminate the land*" when buried; the availability of hand-washing stations; the origin and causes of the virus; how to distinguish Ebola from other common illnesses including AIDS; how to quarantine suspected health zones; how to protect specific vulnerable groups; when people should call for help if somebody falls ill; the difference between the different strains of viruses in Guinea and Equateur; and for more information about response processes.

[v] In December 2018, questions coded in the 'Other' category included requests for advice about how to monitor livestock to prevent Ebola; issues about the resistance of the virus; if the virus is real; if the virus was resistant; if the government vaccinated soldiers and police; what the difference is between poisoning and Ebola; why awareness measures are not more effective; who first discovered the virus; concerns around the provision of free health care; and concerns about not having sufficient nutritional intake if people did not have access to bushmeat.

[vi] In January 2019, questions coded in the 'Other' category included how response workers saw differences between Ebola and other common illnesses; why people stopped shaking hands; why doctors were always foreign; how many kinds of Ebola strains exist; concerns around families hiding suspected cases and material possessions of the deceased from response teams; why people were not able to vote during elections; what happens when Ebola is over; how to become a member of the Red Cross and if the organisation will continue to work when the emergency is declared over.

[vii] In February 2019, questions coded in the 'Other' category included why private hospitals were closed; why the response used violent measures including tear gas; why the outbreak was continuing and when it would be over; why response actors did not listen to the messages from the population; why leaders were complacent about hygiene measures; issues concerning 'Ebola money'; concerns that the affected areas would be able to vote after the outbreak; how people can provide care for their sick (e.g., home care); how best to trust responders; and why there was a frustrating lack of response from the government.

Community suggestions

Suggestions made by community members participating in engagement sessions and during regular household visits by Red Cross volunteers were also collated by the IFRC (with support from CDC). The table below presents the themes of the most frequently made suggestions during community feedback gathered by Red Cross volunteers between November 2018 and 9 February 2019 (rank 1 being the most frequently raised theme). During the reporting period 8,156 suggestions were identified in the data. The most frequently cited suggestion involved expanding or modifying the vaccination programme.

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

	November 2018	December 2018	January 2019	9 February
	6,170 codings	7,434 codings	5,079 codings	1,694 codings
	Beni, Bunia, Butembo, Kasenyi,Katwa, Mabalak, Mandima, Masereka	Beni, Bunia, Butembo, Katwa, Komanda, Mabalako, Mandima	Beni, Butembo, Katwa, Komanda	Beni, Butembo, Katwa, Mabalako, Masereka, Musienene, Oicha
Rank 1	Expand or modify vaccination programme	Expand or modify vaccination programme	Other[viii]	Other[viii]
Rank 2	Other[viii]	Other[viii]	Encourage handwashing	Expand or modify vaccination programme
Rank 3	Encourage handwashing	Encourage handwashing	Expand or modify vaccination programme	Community health promotion
Rank 4	Community health promotion	Community health promotion	Improve health care	Improve health care
Rank 5	Improve health care	Improve health care	Community health promotion	Encourage handwashing

The following is a selection of frequently made suggestions (clustered by key theme, not in order of frequency) as documented in the community feedback gathered by the Red Cross (with support from CDC) and by Oxfam, between November 2018 and 9 February 2019. It also includes questions asked by participants included in qualitative research done by the Communications Commission, IPC-WASH Commission, IRC, Oxfam, Medair, Mercy Corps, UNICEF and WHO.[2] A key suggestion that communities continue to make relates to the detail of information that is provide to them about the overall response. They also emphasise that issues raised by affected communities, particularly concerning the behaviour of response teams, must be considered seriously and acted upon.

Community health promotion Inclusion of groups in efforts, type of platforms used, language	Outbreak control teams should work with chiefs and leaders. Healthcare workers should do radio shows to console the population. Send videos about the Ebola epidemic to everyone's telephones. We suggest you transfer your Ebola promotion films in the downloading booths where people sell music and movies on flash drives so that we can distribute them free of charge. Can the response team also raise awareness in hotels, bars, and restaurants? Bring us pictures of people who are dying of Ebola here and not your leaflets. Send us outreach workers who are able to speak in our mother tongue. Please explain the role of each NGO to us. You should include military camps and prisons into the response efforts.
Response processes Behaviour of response workers, inclusion of local leaders, request for privacy	You must come to raise awareness politely, not come to impose yourselves on us – the first response team was brutal and we hope that the current one continues with more understanding and collaboration. We ask that if there is one dead person, the people from the SDB team arrive quickly because they cause delay. We ask that the response avoids the delay in the analysis of the sample in cases of death. Why not strengthen the investigative team so the results come in on time? Instead of free healthcare or vehicles, bring us the vaccine. Limit the number of vehicles when investigating a suspected case.
Vaccines Equity, discrimination and favouritism	Everyone must be vaccinated. We want the vaccine to be given to everyone, whether they are sick or not. We ask that vaccines be distributed to everyone without discrimination – sometimes people favour their own. The vaccine team should work with chiefs / leaders as they are the driving force of any activity in their community.
Diagnosis and treatment Quality of care, including local health care workers,	We recommend that the rapid screening test be available everywhere. Bring us the medications to protect us against this Ebola. Link local nurses and traditional healers to the response – "*we want our own doctors, not foreigners*"; Be cooperative and show tolerance toward patients so as not to sow a spirit of resistance among the people. Please instruct nurses concerning the reception of certain patients, their way demoralises certain people. Nurses neglect other diseases when you come for treatment in the ETC, or they let you wait a long time before you can get treatment. Increase the group of psychologists in the community to ensure a stable society.
Burials Behaviour of response workers, cultural appropriateness, transmission	We want the laboratory exams to be done first, before the burial. Teach us how to bury the bodies like you do. The police shouldn't be present at burials, even when there is a case. Why are women not part of the safe burial teams? The SDB team should contain a Muslim so that the Muslim funeral rites can be respected too. Despite the difficulties encountered, the SDB team should always have attendance by family members or witnesses to avoid rumours.
Encourage hand washing Vulnerable populations, requests for resources	Bring handwashing stations for each household, as well as for public places like roadways, churches, schools and restaurants. The displaced people don't have soap for handwashing The 'pygmies' also need handwashing stations and soap
Other suggestions Emergency planning, resource distribution, self-care	Provide protection materials in case the emergency team does not come on time or the ETC is far (for those who live in the bush) You need to do the home visits with a person who's recovered Thank you for helping us but create jobs for all of us in the response, not just for the humanitarian workers.

[viii] In November 2018, suggestions in the category 'Other' included requests that the government should exterminate all bats; that bushmeat should be banned; greater access to rapid Ebola tests; and increased efforts from the response. In December 2018, 'Other' suggestions included the provision of free mosquito nets by the government; increasing the hours response teams work; and ensuring response vehicles are not escorted by police officers. In January 2019, 'Other' suggestions included strengthening specific response teams; engaging specific groups in awareness efforts; and establishing water facilities. In February 2019, 'Other' suggestions included reinforcing response teams; telling communities the "*truth about Ebola*"; including Red Cross volunteers in ETCs; reducing the number of vehicles that arrive to collect a patient; not having response teams accompanied by the police; and improving interpersonal communication so that response works spoke "*using a normal* [tone of] *voice, without threats"*.

Key findings

Awareness of Ebola: General awareness of Ebola continues to be high, including in newly affected areas and surrounding cities and towns. A survey by Harvard Humanitarian Initiative (HHI) in October 2018 found awareness to be variable in urban centres outside the *Grand Nord*.[3] Awareness levels were very high in Bukavu (where 87% of respondents knew about Ebola) and Bunia (85% of respondents), but were significantly lower in Uvira (67%) and Goma (58%). Another survey by HHI in December 2018 found that general awareness levels had increased to 74% in Goma, but had decreased in the other three sites (to 85% in Bukavu; 74% in Bunia; and 58% in Uvira).[4] The increased level of awareness in Goma, the regional capital, is important given the proximity to areas affected by the current outbreak and widespread trade links. Knowledge, Attitude and Practice (KAP) surveys led by UNICEF also indicated high levels of general awareness about Ebola. In December 2018, 85% of respondents in Komanda knew about Ebola (although awareness was lower in villages with no active cases), and 78% of respondents in Oicha in January 2019.[5] In areas where case numbers have fallen over time, such as in Beni, Red Cross community feedback data from December 2018 started to include questions about whether the disease had been controlled and when the epidemic would end.

Knowledge about Ebola: Knowledge of basic transmission modes, signs, symptoms and prevention practices appeared to be higher in areas with active cases and longer exposure to the disease and response teams. HHI's October 2018 survey that was conducted in four major cities neighbouring the active epidemic zone (Bunia, Bukavu, Uvira and Goma) identified important gaps in preparedness and readiness efforts, particularly in Bukavu, Uvira and Goma.[6] Across all sites, few respondents reported having good knowledge of Ebola and most did not feel sufficiently informed: 59% reported physical contact with an infected person as a main transmission route, but 54% also identified handling/eating bush meat as a main transmission route, compared to contact with bodily fluids (25%) and sexual intercourse (14%). Across multiple questions, knowledge levels appeared much higher in Bunia compared to the other three cities (Bunia only reported its first case in February 2019, four months after the survey was conducted). Rapid qualitative studies in Beni (October 2018) found a strong perception of increased risk for young children and pregnant and breastfeeding women, linked to their role as caregivers and their exclusion from the formal vaccination campaign.[7] Women and girls also reported being marginalised and worried about Ebola infection during menstruation, including fearing that menstrual blood may be a sign of Ebola.[8] Red Cross community feedback data highlighted that community members in Beni and Butembo viewed the closure of schools as responsible for increased transmission in children as it prevented their follow-up, monitoring and protection as well as preventing proper education. When schools reopened, community members in Beni continued to ask what else the response was doing to protect children.[9] Community feedback from Bunia (November 2018) and Komanda (December 2018) included more comments about Ebola being a supernatural disease, related to demons and witchcraft, than was reported in community feedback from other areas in the same time period (Beni, Kasenyi, Masareka, Rwampara, Katwa, Mabalako, Musienene, Butembo, Madima, Oicha). The UNICEF KAP surveys in Katwa and Kalunguta (December 2018), Komanda (December 2018) and Oicha (January 2019), all newly affected areas when the surveys were conducted, also highlighted important gaps in knowledge.[10] In Komanda, 16% of respondents in affected areas and 37% in non-affected areas were unable to name any mode of Ebola transmission. A low percentage of respondents in affected villages could name three or more modes of transmission (49%), signs / symptoms (64%) or prevention practices (54%), and this proportion fell significantly in unaffected villages. Few reported that family members of affected people (42%) and 'health agents' (34%) were at higher risk of Ebola. In HHI's December 2018 survey, only 26% of respondents from across North Kivu, South Kivu and Ituri, who had heard about Ebola, felt sufficiently informed about it.[11] In Oicha (January 2019), 41% of respondents in the UNICEF-led KAP reported that they should not touch a sick person or their objects without protection; 36% that they should not eat dead animals found in the forest; and 37% that they should avoid shaking hands to prevent Ebola.[ix] Red Cross community feedback data from the reporting period continued to highlight communities' evolving information needs with many participants articulating more complex questions around transmission, care and prevention, particularly in more 'experienced communities' (e.g., those who had been directly affected and/or affected for longer). Yet, a high degree of confusion persisted about how Ebola relates to other diseases with similar symptoms, such as malaria, typhoid, cholera and HIV/AIDS, particularly when a child is sick with mild symptoms such as fever and diarrhoea.[12]

Prevention behaviours: The available data does not allow the systematic tracking of changes in behaviours or the effectiveness of particular community engagement strategies over time.[x] In cities surrounding the epicentre, the HHI survey (October 2018) found that the risk of Ebola did not have a significant effect on risk behaviours, although some behaviour changes were reported.[13] In Bunia, 70% of respondents reported more frequent hand washing, 42% reported social distancing with people suspected of visiting Ebola affected areas, and 42% reported avoiding dead bodies due to Ebola. Qualitative data from Beni, Butembo and Tchomia (October 2018) indicated that women understood Ebola can be passed to a child through breast milk, but confusion surrounded when and how to wean babies safely and many women reported a lack of money for alternative baby milk (powder), even when it was recommended.[14] It is unclear how widely people are using condoms as Ebola prevention practices, but the Red Cross data included a number of requests for condoms to be provided as part of response efforts (e.g., community feedback from Katwa, December 2018). Community feedback also highlighted the desire of many communities to better understand sexual transmission specifically related to survivors (e.g. community feedback from Beni, November-December 2018). In Katwa and Butembo (January 2019), qualitative data highlighted the strong links communities made between access to materials and supplies (particularly water, disinfectants and IPC kits) and their ability to follow prevention recommendations.[15] Red Cross feedback data corroborated these findings with multiple requests reported for more WASH materials at the household level but also in public areas.

Care-seeking during Ebola: The available data continue to show a protracted delay from the onset of symptoms to reporting and to presentation at an ETC and in Ebola-affected communities, self-treatment, traditional healers and pharmacies often remain the first route of care.[16] Qualitative data from Beni, Butembo and Katwa (conducted between October 2018 to January 2019) highlighted that even when people had good knowledge about Ebola, it could take multiple days for them to reach a health facility with triage.[17] Financial and access barriers, including distance to a facility, also prevented early care seeking and qualitative work in Beni (October 2018) found that maternal perceptions of facility capacity, hygiene and availability of equipment and drugs also impacted care-seeking practices, particularly when children were sick.[18] A UNICEF-led KAP survey (December 2018) concluded that a lack of money to pay for care was the most significant issue in Katwa (62% of respondents) and Kalunguta (58% or respondents).[19] A sense of fear and

[ix] Only 12 of the 26 health zones in Oicha were accessible to the KAP survey team at the time in January 2019 due to insecurity. Whilst data from the remaining 14 health zones were unavailable, it is likely that knowledge and awareness was lower in these areas due.
[x] Different data sets measure different indicators and often questions have not been asked in the same form making comparisons challenging.

mistrust in health services and avoidance of health centres and health staff continued to be reported. Data from Komanda (UNICEF KAP, December 2018) suggested that as the virus moved to new areas, a cycle of fear of infection at health centres repeated itself. At the time of writing, nosocomial transmission remains a major concern, with healthcare workers continuing to be infected.[xi] Community members continue to call for the Ebola response to "*give*" them *"protection materials*" so they can self-protect if response teams are delayed or unable to reach the affected community, particularly those '*in the bush*' (Red Cross community feedback data, Beni, December 2018).

Engagement with public health facilities: The data strongly converges on community perceptions about the introduction of free healthcare. Qualitative data suggests that communities value free healthcare and may, in some cases, have more quickly sought care because of it.[20] At the same time, however, data suggests that the policy overwhelmed the public health system, with challenges reported around long waiting times, limited triage and IPC capacity, a lack of attention for patients and the limited availability of medicines.[21] Data from a study in Beni indicated that across 18 clinics, patient numbers from July to October 2018 had increased over 100% in 10 facilities, and upwards of 780% in one.[22] Despite communities' appreciation for free healthcare, the perception that "*free care is of poor quality*" was widespread and the community feedback data reported by the Red Cross suggested that confidence in the health system may be decreasing. In January and February 2019, for example, community feedback data from Butembo and Katwa highlighted a considerable level of suspicion around free health care ("*why is treatment free during election period?"*; "*why is care free in the ETC?*") paired with concerns about the intentions of nurses, politicians and other response workers. As highlighted in a number of studies (November and December 2018) health workers in Beni, Katwa, Kalunguta and Butembo reported feeling under-trained to manage the epidemic, did not have sufficient protective equipment and materials (including water, hygiene kits, essential drugs), were inadequately supervised, lacked staff due to absentees, did not receive their salaries and felt unable to properly care for patients.[23] Given their elevated risk profile, health workers remained concerned for their own safety and the safety of their families, and there were a number of reports that medical staff refused to touch patients, or had to spend their own money on gloves and other protection material.[24] Community members also suggested that, in general, Ebola was being 'over-diagnosed' and that "*all fevers end up being Ebola*". This has contributed to fear about the triage process: "*nurses no longer give proper care, they prefer to direct patients directly to the ETC without even giving first aid even if the patient does not show the signs of Ebola"*.[25] Local impressions that health staff are *"working for Ebola",* implying that they are benefiting financially and therefore perpetuating the outbreak, continue to be expressed in the community feedback.

Engagement with private health facilities and traditional healers: Some community members who participated in qualitative research in Beni expressed their preference for attending private health facilities where they perceived there to be *"Good follow-up; at every moment he comes to see you and will touch you. At the public* [facility], *they look at you as if they do not know you"*.[26] As in public health facilities, patient attendance numbers have risen at private facilities during the outbreak and despite poor IPC measures, there is a perception that paying for health care guarantees better quality services (as opposed to the free healthcare at public facilities).[27] Community members stressed the need to better link the response to private providers ("*our healthcare workers"*). Although the studies did not explicitly investigate community level understanding of IPC, community members continue to call for the response to provide IPC materials and to support IPC practices, potentially through incentivisation, including bonuses for referrals and free drugs.[28] Survey findings from Komanda (UNICEF, December 2018) concluded that indigenous peoples, who may be particularly suspicious of outsiders/foreigners, reported to rely more on traditional medicines.[29] There remained very limited data regarding the role of traditional practitioners or midwives.

Knowledge and perceptions about Ebola treatment: Communities continue to have many questions about the existence, availability and efficacy of Ebola treatment. In the UNICEF KAP conducted in Oicha (January 2019), only 40% of respondents knew where to take an Ebola case to be treated.[30] A multitude of questions around the type and quality of treatment in Ebola Treatment Centres (ETCs) were recorded across the data sets. Most centred on survival and death rates although questions focused on practical issues remained common ("*Do you need to pay for care at an ETC"*; "*How do patients receive food?*"). Questions around the availability and location of ETCs were also reported, with people in some affected areas (e.g., Oicha and Mabalako) asking: "*Why is there no ETC here?"* (Red Cross community feedback data, November-December 2018). The Red Cross data continued to highlight communities' concerns about ETCs and the perception that there was a low survival rate after admission. This was particularly pronounced in Red Cross community feedback data from Butembo, Katwa, Komanda and Oicha gathered across the reporting period. In Katwa in January and February 2019, for example, statements such as "*There are no cases who have returned from the ETC*" and "*It is not possible to visit the sick at an ETC*" were regularly reported. Communities continue to fear ETCs, perpetuated by the circulation of misinformation. Even in communities that have been exposed to Ebola for a longer time (Beni, Butembo), negative perceptions about ETCs remain, although it is difficult to ascertain from the data how widespread these are. Community feedback continues to highlight issues associated with long waiting times prior to admission and delays in positive diagnosis; concerns over lack of food and water for patients; concerns about the lack of family involvement (particularly when young children are admitted) and failure to keep family members updated; uncaring and 'brusque' staff attitudes; and concerns about the type and quality of care (with reports that body parts are removed and that body bags are the cause of death). In the community feedback data, there continues to be reports that community members may be accused of 'murder' if they call an Ebola ambulance or take a patient to an ETC. It is unclear how community members (including patients and affected families) perceive the various experimental therapeutics being deployed in the outbreak, or how they understand issues of informed consent and risk.

Knowledge about the Ebola vaccine: Acceptance of the experimental Ebola vaccine was widespread and requests to expand the vaccine campaign were consistently reported in the Red Cross community feedback. However, there remained limited understanding at the community level about how the vaccine was being deployed, who was vaccinated, when and why. In the UNICEF-led KAP in Komanda (December 2018), 76% of respondents in areas affected by Ebola knew that there was a vaccine but 56% of those reported that 'everyone' could receive it.[31] Community members were also aware that the vaccine had been introduced in countries neighbouring DRC (e.g. Uganda) but the strategy around who was receiving the vaccination and why continued to create confusion and fuel suspicion about the government and health worker motives. Community feedback included multiple explanations and interpretations of vaccination: that there were two vaccines (a good one for doctors and a bad one for the community); that the vaccine could kill you (it is a weapon to spread the virus); and that side effects of the vaccine included impotence, sterility and disability. Issues

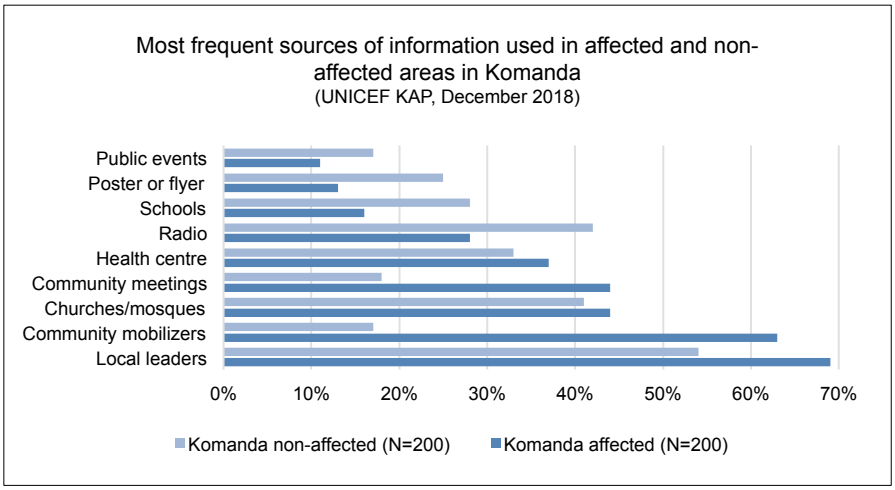
[xi] By 24 February 2019, a total of 69 health workers had been infected with 21 deaths (WHO SitRep 30).

around power dynamics and decision-making were also highlighted in community feedback and focused on who was / was not on a contact tracing list and why, and whether this made them (in)eligible to receive the vaccine. In the Red Cross community feedback, delays in receiving the vaccination were reported, and there were multiple comments that the vaccine teams prioritise their friends and family and were 'disdainful.' In part, this may be a result of the vaccine teams working predominantly in French, a language associated with the higher-educated elite and which has connotations with colonialism, and government and military authority.[xii] Community leaders in Oicha also reported that vaccination teams started work without engaging local leaders: *"The vaccination teams showed up in my village, without announcing themselves. They started work without seeing me*, [thinking they can work] *without the chef.* [But] *in case of problems, who will they call?"*[32] The UNICEF-led KAP in Katwa and Kalunguta (December 2018) found that there was initial reluctance from health workers to be vaccinated at the beginning of the response and that, although most had since been vaccinated, potentially up to 30% remained un-vaccinated and vaccination teams were reluctant to vaccinate those who initially refused.[33]

Vaccinating pregnant and breastfeeding women and young children: Red Cross community feedback and other qualitative data indicated communities' widespread belief that the exclusion of pregnant women, breastfeeding women and children under one from the vaccination protocol made these groups particularly vulnerable and contributed to disproportionately high infection rates.[34] At the community level, there appeared to be little understanding of why these groups were excluded, and this generated additional concerns that were layered over the broader community concerns regarding vaccination (outlined above). A study in Beni, Butembo and Tchomia (October 2018) found that in 9 out of 13 focus group discussions, women mentioned knowing someone who had been a contact but was never followed-up for vaccination due to their pregnancy or breastfeeding status.[35] Participants stressed that pregnant and breastfeeding women were fearful of infection and avoided going outside ("*You tell us to protect yourself with the vaccine, and then you tell us we cannot get the vaccine. So we have nothing left"),* whilst others reported to have (temporarily) weaned their children in order to receive the vaccine, even though this incurred significant out-of-pocket costs related to the purchase of milk powder and put them at risk of social criticism.[xiii] Although the protocol was changed to include pregnant and breastfeeding women and children under one in January 2019, at the time of writing (March 2019), the operational strategy in North Kivu was yet to be updated. Qualitative data showed that changes in the vaccination protocol need to be carefully managed at the local level, that the wider community must be sensitised to the new vaccination strategy and that careful explanations must be given as to why pregnant and breastfeeding women and children under one will now be included.

Burial practices: Concerns and fears surrounding safe and dignified burials (SDB) continue to be reported by community members and response partners. The UNICEF-led KAP in Komanda (December 2018) found that 35% of respondents in affected villages had not heard about safe and dignified burials, revealing a critical gap in knowledge about risk, protective practices and response activities.[36] Across all qualitative studies made available for this data compilation (data collected between October 2018 and January 2019 in Katwa, Kalunguta, Oicha, Komanda and Beni), community members expressed concerns about how response teams entered their neighbourhoods and their limited engagement with local leaders and the affected population. Communities continued to question why the police or military were present during burials and why bodies were '*taken by force into the ambulance.*'[37] In newly affected areas, Personal Protective Equipment (PPE) continued to contribute to fears about the SDB teams, and long waiting times between the alert being made and a team's arrival continued to be reported. The need to modify SDB protocols to include local burial and funeral practices is well understood, but is not always done effectively. Studies from Katwa and Kalunguta (December 2018) included reports that bodies were being buried '*in disorder*' with examples given of bodies being incorrectly aligned in the grave (e.g., not with their heads facing the village or mountain); that bodies were not being prepared properly and/or were being buried in 'dirty' clothes; and that mourners were not allowed to throw earth on the corpse or coffin.[38] In some communities, people continued to be concerned that a pregnant woman would be buried without first removing the foetus.[39] The analysis of data from focus groups led by UNICEF in Katwa and Kalunguta (December 2018) emphasised that the management of funeral rituals must include key actors from the family and community, and as reported in the Red Cross community feedback data from Beni, "*The natives should lead the specialists*" (December). Two key requests that were consistently highlighted in the feedback data were a) "*teach us how to do these burials ourselves*"; and b) ensure that response teams (including but not only SDB teams and nurses) were "*more compassionate"* and did not behave inappropriately at burials.

Sources of information: Across the KAP surveys led by UNICEF in Katwa and Kalunguta (December 2018), Komanda (December 2018) and Oicha (January 2018), radio, churches, health centres and community channels are cited as the most common sources of Ebola-related information, although there were variations between studies and field sites. In the Komanda survey, differences in communication channels were evident when comparing affected and non-affected communities, and in recently affected areas, community mobilisers were the most widely cited source of information on Ebola (see graph).[40] All KAP surveys have shown very low exposure to pamphlets, flyers and posters and there remains concern, as highlighted in the qualitative studies,



[xii] Translators without Borders (TwB) conducted an initial language and communication assessment in Goma in February 2019. The research was designed to identify the languages and formats best understood by different sectors of the community. The findings should be operationalised to ensure that people have access to information in a language they understand and can communicate with responders on their needs and concerns. TwB will publish their report by mid-March and key findings will be included in the next data compilation brief (scheduled for May 2019).

[xiii] Exclusive breastfeeding for the first two years old life is a social norm in North Kivu. Ceasing breastfeeding before the child is 24 months old may result in the mother being suspected of infidelity, accused of demonstrating a lack of love for her child and family and disrupting social relationships. As one participant noted in the study, "*Any child who has not been breastfed enough* (i.e., for two years) *by her mother will be silly and a dunce for life. Sometimes at school, we challenge any child with academic difficulties who has not been sufficiently breastfed by his mother*". From 'Qualitative data on the perceptions EVD risk, exposure and prevention among pregnant/lactating women', Beni, Butembo and Tchomia, 22-28 October 2018, by Communication Commission, Oxfam, Medair, IRC, UNICEF.

that there is limited involvement of and direct engagement with women in communication campaigns.[41] The UNICEF-led KAP survey in Katwa and Kalunguta (December 2018) found that less than 20% of participants reported to have had volunteers teach them about Ebola during door-to-door activities.[42] Community suggestions recorded during Red Cross community feedback include requests for more health promotion in restaurants; enhanced engagement with community and religious leaders; renewed training of local health workers to be able to provide detailed information to communities; and support for both visual materials (including photographs and film) and radio.

Perceptions about the response and community involvement: The Red Cross community feedback included many statements of gratitude and encouragement for response teams involved in health promotion, burial teams and access to healthcare (6,512 expressions of gratitude and encouragement from Beni, Butembo, Komanda, Mandima, Musienene, Rwampara, Bunia, Katwa, Mabalako, Maserka and Oicha between 21 August 2018 and 20 January 2019). Comments made it clear that communities appreciated the political and security challenges response teams faced. They demonstrated increased levels of knowledge about the outbreak and response, as well as acknowledgement that the number of cases was decreasing in some areas. Such positive comments co-existed, however, with ongoing criticism, complaints and statements of unmet expectations. Indeed, some qualitative data suggested a decrease in community levels of confidence in response teams in certain areas and over time, largely associated with the perceived lack of dialogue around vaccination, surveillance, decontamination and burials, and concerns about the technical capacity of response staff.[43] The need to work with local people is continually emphasised, including *relais communitaire* with whom the community already has an established relationship. Community members also point to an apparent lack of coordination in some response efforts, and confusion about the different roles of the multiple agencies and NGOs also continues. Convoys of 'large vehicles' that arrive suddenly to search for a contact, to collect a suspected case or to perform a burial, are frequently referred to throughout the community feedback as being intrusive and causing disturbance. As reported in the Red Cross feedback from Katwa (December 2018) "*We don't want the car procession during response activities".* The view that *'Nothing is private* [with Ebola] *while malaria and typhoid are managed more discreetly*' appears widespread (Red Cross feedback data, Butembo, December 2018). The burning of possessions in front of a house was understood to be particularly troubling. The high visibility of the response was also linked to suspicions and concerns about money-making and political motives, and to the reduced trust between neighbours (associated with people making alerts) which could magnify existing tensions.[44]

Trust and misinformation: The HHI survey (December 2018) found that 41% of respondents in Ituri agree with the statement that 'Ebola did not exist', 14% in North Kivu and 11% in South Kivu although the rates were much higher in urban centres (17% in Butembo and 68% in Bunia).[45] Red Cross community feedback data indicated that the ongoing insecurity and lack of trust remained major systematic barriers to Ebola response efforts, particularly in Katwa, Butembo and Komanda and continued to include statements such as "*We don't trust our government, which is why we doubt everything it may do for the community"*(Red Cross community feedback data, Katwa, early December 2018); "*Ebola is the work of the government to finish off the population*"(Red Cross community feedback data, Oicha, December 2018); "*The Ebola virus disease was sent here by the Kabila government to take revenge on the people of the great North Kivu, because he understood that he is not welcome here"* (Oxfam community feedback data, Kasanga Benenguli in Beni, collected between 3-18 January 2019); and "*The community also does not trust the response team"* (Oxfam data, Ngongolio/Kangaembi, 3-18 January 2019). Whilst it is difficult to ascertain from the community feedback data how dominant such views are, it is worth noting that in December 2018, the highest rank of concerns in the Red Cross feedback data from Beni (one of the first affected areas) was still focused on the perception that Ebola was a scheme of the government. Red Cross community feedback data also reported concerns about "*White people and international NGOs*" spreading Ebola as a strategy "*to eradicate the Nande people*" (Bunia, November 2018, and Komanda, December 2018). Ebola has been increasingly seen as an organised business that will not end because the response teams inflate case numbers for financial gain; in Beni, classifying non-infected people as having Ebola was frequently mentioned in the community feedback as a means of extending the response (Red Cross community feedback data, December 2018 and January 2019).

Methods and limitations

In general, there was a very high degree of convergence in the datasets regarding key themes and issues. The Red Cross and Oxfam community feedback was based on identifying broad trends. In those data sets, it is unknown whether comments were made repeatedly by the same individual, how representative the sample was, or how many respondents made no comments. Overall, however, the material has been triangulated across sources whenever possible. The brief also relied on data and analysis from a previous data complication brief based on similar types of data sources collected between August and October 2018 (see https://opendocs.ids.ac.uk/opendocs/handle/123456789/14144) as well as from secondary data (including other SSHAP briefs).

A number of important limitations must be acknowledged. For several of the surveys and qualitative data included, study design and methodologies were not available for review. The surveys often asked different questions or framed questions in different ways, which made direct comparisons challenging. The available surveys were from newly affected areas (Komanda, Oicha, Katwa: UNICEF data) and neighbouring cities (HHI data) and not from areas previously surveyed (Beni and Butembo). This prevented the systematic analysis of longitudinal data. In most cases, we did not have access to the raw data and had to rely on power-point presentations or reports of major findings, therefore limiting our independent analysis. Other limitations include uncertainty about how the questions were posed to participants (e.g. as open or closed questions); a lack of clarity on how geographical locations may have influenced certain findings; and concerns about accuracy of translation. Lastly, it is unclear how representative many of the quotes and findings are, although given the effort to triangulate between sources they are illustrative.

Contact

If you have a direct request concerning the response to Ebola in the DRC, regarding a brief, tools, additional technical expertise or remote analysis, or should you like to be considered for the network of advisers, please contact the Social Science in Humanitarian Action Platform by emailing Juliet Bedford (julietbedford@anthrologica.com) and Santiago Ripoll (s.ripoll@ids.ac.uk). Key Platform liaison points: UNICEF (kchitnis@unicef.org); WHO (bhatiaseviap@who.int) and (barryr@who.int); IFRC (ombretta.baggio@ifrc.org); Communication Commission in DRC (jdshadid@unicef.org); GOARN Research Social Science Group (nina.gobat@phc.ox.ac.uk).

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Studies included

Data and analyses were extracted from 12 sources, including four quantitative knowledge, attitude and practice (KAP) surveys (led either by UNICEF or HHI); rapid qualitative data collected by the Communications Commission, IPC-WASH Commission, IRC, Medair, Mercy Corps, Oxfam, UNICEF, and WHO; and routine (ongoing) qualitative community feedback collected by the National Society of the Red Cross in DRC with IFRC support (and in partnership with CDC for the coding and interpretation of data) and Oxfam. Data were generated in the following health zones: Butembo, Bunia, Kasenyi, Katwa, Komanda, Mabalako, Mandima, Maserka, Musienene, Ngadi, Oicha and Rwampara in North Kivu and Ituri provinces and were shared through the Risk Communication and Community Engagement coordination group for the Ebola response in the Democratic Republic of Congo.

Studies included in this rapid compilation of social science and behavioural data:

Organisations	Study description	Timeframe of data collection	Location	Data
Communication Commission, Oxfam, Medair, IRC, UNICEF	Qualitative data to understand barriers and motivators to health seeking for children, and exposure and prevention of risk	17-21 October 2018	Beni (Ngongolio, Butanuka, Malepe and Rwangoma)	12 focus group discussion with mothers (9), fathers (1) and FOSA staff (2)
Communication Commission, Oxfam, Medair, IRC, UNICEF	Qualitative data on the perceptions EVD risk, exposure and prevention among pregnant/lactating women	22-28 October 2018	Butembo, Tchomia and Beni (Ngongolio, Butanuka, Malepe, Butsili and Rwangoma)	12 focus group discussions with mothers (9), fathers (1) and FOSA staff (2)
Communications Commission and WHO	Rapid anthropological study on vaccination in pregnant/lactating women and children under one	20 – 24 November 2018	Beni (Tamende, Kalinda, Ngongolio, Benengule, Kanzuli and Vingazi)	Qualitative surveys (n=135: 70 women and 65 men) Focus groups with pregnant & breastfeeding women Focus groups with men and fathers Interviews with caregivers and midwives Door to door visit to 30 randomly selected households
Communications Commission, IPC-WASH Commission, UNICEF, WHO, Oxfam, Medair, IRC, Mercy Corps	Qualitative data on perceptions of access to, use and quality of health services	23-28 November 2018	Beni	11 focus group discussions, with 103 participants (7 women and 4 men groups) 21 FOSA sampled (private and public) for patient intake numbers from July – November
HHI	Survey – focus on Ebola	October 2018	Goma, Bukavu, Uvira and Bunia	N=1,112
HHI	Survey – focus on Ebola	Dec 2018	25 towns and territories across the provinces of Ituri, North Kivu and South Kivu	N=5,852
IFRC/Red Cross	Online community feedback dashboard containing qualitative perceptions data.	November 2018 – 15 January 2019	Beni, Mabalako, Butembo, Bunia, Kasenyi, Katwa, Musienene, Maserka, Rwampara, Mandima, Komanda, Oicha, Ngadi.	Dashboard access can be requested from Ombretta Baggio (see contact details below). A total of 99,210 data points have been recorded over the response.
IPC-WASH Commission UNICEF, WHO, IRC, CARITAS	Qualitative data focused on perceptions of access to, use and quality of health services (new and old) since the outbreak and response interventions	25-31 January 2019	Katwa and Butembo	13 focus groups with 77 participants. Groups included response teams, FOSA staff, women's associations, women leaders.
Oxfam	Community feedback data collected by OXFAM staff members during programme visits.	3 Dec 2018 -25 Jan 2019	Beni (Mabolio, Butsili, Malepe, Madrandele, Bundji, Ngongolio, Kasanga Benenguli, Kanzuli, Mabolio, Malepe).	Total comments collected: 118. FDGs and KIIs including local authorities, community based groups, youth associations, tradipracticiens, women associations, community health care workers. Mixed sample in terms of gender (majority were women), age (majority adults) from affected and non-affected communities – with most participants not classified as "affected by Ebola"
UNICEF and Communications Commission	KAP study, and qualitative research focused on risk factors for women and kids and community perceptions of the response	2-10 December 2018	Katwa and Kalunguta	N=400 mothers of children under 5 years old, in 38 villages 7 focus groups with mothers with kids under 5 8 interviews with local leaders and influencers. Participant observation in health centers
UNICEF and MOH DRC	KAP study, and qualitative study focused on EVD transmission and prevention	20-24 December 2018	Komanda	Random sampling in 36 villages in 8 health zones (n=400, half in 4 health zones affected by Ebola and half in 4 non-affected health zones) 7 FGDs (4 women/3 men, each with 8 participants = 56 people Participant observations at 8 health clinics Structured interviews with 8 local leaders
UNICEF	KAP study, and qualitative study focused on EVD transmission, prevention and access to health services	22-28 January 2018	Oicha	Survey to n=194 households in 12 health zones 6 FGDs and 10 In-depth interviews, with women and men; young people and RECOS; providers of care, leaders and influencers.

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