BARRIERS AND MOTIVATORS FOR COMMUNITY PARTICIPATION IN THE RESPONSE TO EBOLA IN THE DEMOCRATIC REPUBLIC OF CONGO (DRC), 2018-2019

A synthesis of social science analysis results and corresponding field activities in four response areas. This was a collaborative project led by CDC's Social and Behavioral Science (SBS) Task Force in direct support of the DRC's Ebola response social science analytic cell (see author listing, page 16)

OBJECTIVE

The objective was to identify major barriers and motivators for community participation in the four key interventions of the 2018-2019 Ebola response in eastern DRC: 1) early identification of possible Ebola cases, identification and monitoring of all contacts ("contact tracing"); 2) vaccination of people at high risk; 3) transfer of people with possible Ebola symptoms to an Ebola treatment center; and 4) safe and dignified burial.[1] Analysts reviewed quantitative and qualitative analyses conducted during the response. All available social science reports on community knowledge, attitudes, behaviors, experiences and recommendations were reviewed and the results grouped according the four interventions, and then according what motivators or barriers to participation are suggested by the findings. To be included, motivators and barriers had to be indicated by at least two separate studies or reports. Motivators and barriers are shown according to intervention category in in tables, alongside a summary of current activities and opportunities for further action.

BACKGROUND

A unique feature of the current response to Ebola in the DRC is the large volume of social and behavioral data collected through the social science analytic cell ("Cellule d'Analyse en Sciences Sociale," or "CASS") and community feedback data collected by the Risk Communication and Community Engagement (RCCE) task force. To date, community volunteers have collected more than 500,000 feedback comments (in 17 health zones).[2] In addition, more than 30 qualitative and quantitative studies on perceptions, knowledge, attitudes, and behaviors (Knowledge, Attitudes, and Practices (KAP) surveys, focus groups, etc.,) have been conducted in eastern DRC since the outbreak began. There are also a small but growing number of published studies on perceptions of the Ebola virus disease (EVD) in eastern DRC.[3-5] This report is the first of its kind to bring all of these data together to summarize and align the evidence on barriers and motivators for community participation, and to describe the steps taken to overcome the barriers.

Definitions

Participation, motivators, and barriers

Participation is defined as the ability and willingness to engage with prevention and treatment interventions during the response to an Ebola outbreak. Motivators are defined as factors, either external or internal to an individual that enhance a person's capability, opportunity, or motivation to participate in the interventions. Barriers are defined as the opposite: external or internal factors that impede an individual's capability, opportunity, or motivation to participate.

Ebola contact

An Ebola contact, or simply a "contact," is defined as "...any person who has been exposed to a suspected, probable, or confirmed case of EVD disease in at least one of the following ways: 1) slept in the same household as a case; 2) had direct physical contact with the case (living or dead) during illness; 3) had direct physical contact with the case (dead) at a funeral or during funeral preparation rituals; 4) touched the blood or body fluids (including urine, feces, vomit, tears or sweat) of a case during illness; 5) touched the clothing or linen of a case; or 6) is a baby who has been breastfed by the case."[6]

Participation in contact tracing

In the context of this response, contact tracing is defined as the performance of one of the two behaviors:

1. Among individuals identified as possible or confirmed cases of EVD: providing the name and contact information of one or more individuals with whom they recall having been in contact during the period when they were exhibiting symptoms that meet the case definition of EVD.
2. Among the people identified as "contacts" in point 1 above: agreeing to receive a daily visit for 21 days, to have their temperature taken and to answer questions about the presence of symptoms of the disease. (This does not include consent to transportation to an Ebola treatment center or temporary isolation center).

Participation in vaccination
Participation in vaccination is defined as being identified as a candidate for vaccination and agreeing to have it administered. The "ring" vaccination strategy involves selectively vaccinating only close contacts of suspected cases, including healthcare and intervention workers, as opposed to a geographically based strategy where everyone in a target neighborhood is vaccinated.

Participation in transport to the Ebola treatment center
Participation in transport to an Ebola treatment center is defined as: 1) the willingness to be transported; 2) to have a family member transported to an Ebola treatment center; or 3) the willingness to be immediately transported (or to have a family member transported) to an Ebola treatment center.

Participation in safe and dignified burial
Participation in safe and dignified burial involves following a series of twelve steps established by the World Health Organization (WHO) to prevent transmission, while allowing for family involvement to the greatest extent possible.[7] The key elements of the process are as follows: 1) the family must be fully informed of the dignified burial process; 2) the formal consent of the family must be obtained; 4) personal protective equipment must be worn appropriately; 4) decontamination steps must be followed; and 5) handling of human remains must be minimized.

EPIDEMIOLOGY OF EVD AND INTERVENTION INDICATORS
Despite recent advances in the prevention and treatment[8-10] of Ebola virus disease (EVD), this virus remains highly contagious and deadly.[11-14] In DRC, case totals have fluctuated since the epidemic was declared on August 1, 2018;[12] confirmed cases peaked in May 2019 with 117 cases in one week,[15] fell to their lowest level in November 2019 with 6 in one week,[16-17] and then increased significantly again to 27 cases in December 2019.[18] Current projections suggest that EVD cases could continue in eastern DRC through 2020.[19] The most effective practices to stop an outbreak of EVD are summarized in four key behaviors: contact tracing (and offered vaccination), transfer of suspected cases to Ebola treatment centers (ETC), and safe and dignified burial.[20-22]

Participation in the Four Key Behaviors During the Ebola DRC 2018-2019 Response
Contact tracing
Epidemiological data suggest that not all contacts of Ebola cases were identified or tracked. For example, the contact tracing data reviewed for the period August 1, 2018 to December 31, 2019 revealed that only 46% of EVD cases were listed as known contacts. Another indicator of contact tracing success is the proportion of identified contacts who are successfully followed. Contact tracing data (from Beni, Biakato, Butembo, Mambasa, and Mangina subcoordinations) shows that from June 3, 2019 to December 31 2019, the overall contact follow-up rate was 73%, and the mean weekly contact follow-up rate ranged from 59% (week beginning November 25, 2019) to 84% (week beginning November 11, 2019). The most recent data on contact tracing for the past 21 days (as of December 31, 2019) indicated 70% of contacts were followed-up.[23]

Vaccination
As of January 4, 2020, a total of 261,285 people have been vaccinated against the Ebola virus in eastern DRC.[24] While there are no data available on the effectiveness of a vaccination campaigns in DRC, the data suggest that not all contacts are vaccinated. Other social science data suggest that vaccination is not fully accepted; for example, depending on the area and time period, between 26% and 69% of survey participants in DRC reported that they would refuse vaccination.[3,5]

Early transfer of suspected cases to an ETC
Beni and Bunia did not enter data on alerts that were isolated in the ETC, and most of the data were from Butembo.[25] Based on these data, between January 1, 2019 and December 31, 2019, the percentage of validated alerts (suspect cases) that were admitted to an ETC or were in the process of admission ranged from 12% (week starting January 6, 2019) to 38% (week starting December 8, 2019). As of December 31, 2019, the overall proportion of validated alerts admitted to an ETC or in the process of admission was 27%.[23] Although there has been an overall upward trend in the

proportion of early-isolated EVD cases and a downward trend in community deaths since the beginning of 2019, these data suggest that the challenges of early isolation remain.

Safe and dignified burials

Data on safe and dignified burials from the International Federation of Red Cross and Red Crescent Societies (IFRC) were reviewed. Data from September 22, 2018 to December 31, 2019 showed that 86% of people who died as a result of EVD received a safe and dignified burial. The percentage of safe and dignified burials fluctuated between a high of 96% (week beginning November 25, 2018) and a low of 69% (week beginning March 17, 2019). Of the recorded deaths, 5.0% were confirmed EVD cases by swabbing. Safe and dignified burials were performed even for non-EVD cases, so it is difficult to determine successful practices among confirmed EVD cases. 50% of the deceased received a dignified and secure burial in hospitals, and 51% in other places (such as transit centers, ETCs, and in the community).[26]

METHODS

Theoretical Basis

In this analysis, the concept of examining barriers and motivators for participation was drawn from health behavior specifically, the socio-ecological model[27] and the COM-B behavior system.[28] The socio-ecological model posits that individual decision-making is influenced by family and community beliefs, and suggests that behavioral interventions should act across multiple levels of influence to increase impact. The COM-B behavior model further suggests that health decisions and actions are influenced by an individual's capability, opportunity as well as motivation to perform a behavior. This acknowledges the multifaceted nature of behavioral influences, both internal (psychological) and external (cultural, financial and logistical). The purpose of the current approach of identifying motivators and barriers is to identify a range of influences, both positive and negative, on participation in each of the four interventions.

Social Science Study and Survey Inclusion Criteria

All types of systematic investigation of community KAP, experiences, and recommendations regarding the Ebola response were included in this analysis, spanning published research and unpublished operational studies conducted to support response interventions. Analysts identified published literature, unpublished CASS reports, Red Cross reports in Goma, and qualitative "community feedback" reports prepared by CDC that related to any of the four key behaviors (contact tracing, vaccination, transport to the ETC, and safe and dignified burial). Published reports were identified through PubMed using the search terms 'Ebola', 'Democratic Republic of Congo', 'North Kivu' and '2018' and '2019'. For the purpose of this analysis, all surveys where participants selected predefined response options for the purpose of comparing the frequency of option selection were considered quantitative. All other types of surveys were considered qualitative; these included surveys with questions that were entirely open-ended, or surveys with no questions that allowed for comments and questions to be simply recorded.

Data Synthesis

Analysts first created four tables, each corresponding to one the four key behaviors. Examining the body of qualitative research, they then identified themes that emerged that corresponded to each of the four key behaviors—examples included "belief that Ebola does not exist" or "distrust in the medical system." The themes were then organized by the barrier or motivator to participation that they suggested.

Next, analysts searched the quantitative data for evidence that aligned with each of the motivators and barriers identified from the qualitative data review. The alignment between the quantitative and qualitative research underwent two rounds of validation by analysts to confirm that the data points corresponded.

Analysts then removed all barriers and motivators that were not corroborated by both qualitative and quantitative data. Quantitative and qualitative research methods each pose unique strengths and challenges with respect to the robustness, generalizability, and replicability of the findings. As such, for the purpose of this report, the analysts proposed that only the barriers and motivators that emerged from both the quantitative and qualitative research were to be presented, as these were deemed more reliable and strongly supported than the findings that emerged from one body of research alone.

Unexpectedly, no motivating factors were identified that were supported by both qualitative and quantitative data, so tables and the discussion from this point onward refer only to barriers. Within each key behavior table, the identified

barriers were presented in order of strongest to weakest quantitative foundation. The supporting data for each of the barriers were then summarized and presented in brief bullets, also organized by strength of association.

The analysts then reviewed UNICEF, WHO and CDC situation reports to identify ongoing activities that related to any of the barriers. Summaries of Ebola news from North Kivu and UNICEF's action reporting tools (Monito) were scanned as well, and CDC analysts corresponded via email and phone with UNICEF stakeholders for accounts of relevant activities. Finally, the analysts compared the activities to identified barriers to suggest additional areas of investigation. These suggestions were validated by two other analysts to verify alignment with the barriers mentioned and the reported ongoing activities.

References

1. Damon IK, Rollin PE, Choi MJ, Arthur RR and Redfield RR. New tools in Ebola. New tools in the Ebola arsenal. N Engl J Med. 2018;379(21):1981-1983. DOI: 10.1056/NEJMp1811751
2. Red Cross, DRC and International Federation of Red Cross and Red Crescent Societies (IFRC). Feedback from the community to inform efforts to combat the Ebola virus. Cumulative data set from the feedback system. Accessed 21 January 2020.
3. Vinck P, Pham PM, Bindu KK, Bedford J, Nilles EJ. Institutional Confidence and Misinformation in the Response to the Ebola Epidemic of 2018-19 in North Kivu, DR Congo: A Survey Based on Securing the Population. Lancet Infect Dis 2019; 19: 529-36.
4. Masumbuko Claude K, Underschultz J, Hawkes MT Social resistance favours the persistent transmission of the Ebola virus in eastern Democratic Republic of Congo: A study of mixed methods. PLoS ONE 2019;14(9):e0223104.
5. Harvard Humanitarian Initiative. Voices of Congo, polls Secured Peacebuilding and Reconstruction. Poll 18: April 20 - May 10, 2019.mixed methods study. PLoS ONE 2019; 14(9):e0223104. https://doi.org/10.1371/journal.pone.0223104
6. WHO and Centers for Disease Control. Emergency Guideline: Implementation and management of contact tracing for Ebola virus disease, September 2015. https://www.who.int/csr/resources/publications/ebola/contact-tracing/en/
7. WHO. How to conduct safe and dignified burial of a patient who has died from Ebola or Marburg. WHO Reference number WHO/EVD/Guidance/Burials/14.2. Guidelines October 2017. Available at https://www.who.int/mediacentre/news/notes/2014/ebola-burial-protocol/en/
8. Dhama K, Karthik K, Khandia R, Chakraborty S, Munjal A, Latheef SK, et al. Advances in the design and development of vaccines, drugs and therapies against the Ebola virus. Frontiers in immunology 2018;9:1803.
9. Mendoza EJ, Racine T, & Kobinger GP. The continuing evolution of antibody-based treatments for Ebola infection. Immunotherapy 2017;9(5):435-450.
10. Henao-Restrepo AM, Camacho A, Longini IM, Watson CH, Edmunds WJ, Egger M, et al. Effectiveness and efficiency of an rVSV vector vaccine in the prevention of Ebola disease: final results of ring vaccination in Guinea, open-label, randomized cluster trial (Ebola Enough!). The Lancet 2017;389(10068):505-518.
11. Dean NE, Halloran ME, Yang Y, & Longini IM. Ebola virus transmissibility and pathogenicity: a systematic review and meta-analysis of household secondary attack rate and asymptomatic infection. Clinical Infectious Diseases 2016;62(10):1277-1286.
12. Lefebvre A, Fiet C, Belpois-Duchamp C, Tiv M, Astruc K, & Glélé LA. Case fatality rates of Ebola virus diseases: a meta-analysis of World Health Organization data. Medicine and Infectious Diseases 2014; 44(9); 412-416.
13. Dixon MG, & Schafer IJ. Ebola viral disease outbreak - West Africa, 2014. MMWR. Weekly report Secured Morbidity and Mortality 2014; 63(25): 548.
14. U.S. Government. Democratic Republic of Congo (DRC) Situation reports by the UN Secretary-General. No. 94, 16 January 2019.
15. U.S. Government. Democratic Republic of the Congo (DRC) Situation reports of the UN Secretary-General. No. 59, 16 May 2019.
16. U.S. Government. Democratic Republic of Congo (DRC) Situation reports by the UN Secretary-General. No. 85, 14 November 2019.
17. U.S. Government. Democratic Republic of Congo (DRC) Situation reports by the UN Secretary-General. No. 87, 27 November 2019.
18. U.S. Government. Democratic Republic of Congo (DRC) Situation reports by the UN Secretary-General. No. 89, 12 December 2019.
19. Estimating the number of Ebola cases and proportion of cases in effective isolation, DRC, 2018-2019. Ebola Case Projection Memo V3.25, cleared 2 January 2020.
20. Shrivastava SR, Shrivastava PS, & Ramasamy J. Usefulness of contact tracing in reducing the extent of Ebola disease. Germs 2014;4(4):97.
21. Stamm LV. Ebola virus disease: rapid diagnosis and timely notification of cases are essential for a rapid response to the epidemic. The American journal of tropical medicine and hygiene 2015; 93(3):438-440.
22. Pandey A., Atkins KE, Medlock J, Wenzel N, Townsend JP, Childs JE, et al. Strategies for containing Ebola in west Africa. Science 2014 ; 346(6212) : 991-995.
23. Analysis of WHO Epidemiological Master Line List Data from PCloud. Analysis by Centers Disease Control and Prevention Epi Team, January 10, 2020.
24. WHO. Ebola virus disease: Democratic Republic of Congo. Secured External Status Report #74, 7 January 2020.
25. Analysis of alert data from WHO on PCloud. Analysis by Centers Disease Control and Prevention Epi Team, January 10, 2020.
26. International Federation of the Red Cross (IFRC). Data on safe and dignified burial. Analysis by the team of epidemiologists from the Centers for Disease Control and Prevention, 20 January 2020.
27. Figueroa, Maria Elena. A theoretical socio-ecological model of communication and behavioural theory for the containment of the Ebola epidemic in Liberia. Journal of health communication 2017;22(sup1):5-9.
28. Michie S, Atkins L, & West R. The Behavior Change Wheel. A guide to intervention design. 1st ed. Great Britain: Silverback, 2014; 1003-1010.

TABLE 1. BARRIERS TO PARTICIPATION IN CONTACT TRACING

ack of information on contact tracing

VE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
eys[1-5] the eight subcoordinations majority (>50%) reported not the different interventions the Ebola response (lowest: d highest: 85%, women in	Community Feedback[6-7] Several health zones reported that not understanding the reasons why people's names are written down creates fear and suspicion, and 26% (n=241/914) of the comments on contact tracing indicated that more information was needed. Interviews and Focus Groups[8] Many in Butembo and Katwa indicated that people need an explanation of what contact tracing is: 15% of the interviews and 33% of the focus groups reported a lack of information about the Ebola outbreak in general.	A "frequently asked questions" (FAQ) document has been distributed to contact tracers and is used in training.[9] An adaptation of a video created for the epidemic in West Africa, with an appropriate "dub" for the DRC has been developed and distributed.[10] The Risk Communication and Community Engagement (RCCE) teams have undertaken educational efforts in Biakato, Bunia, Butembo, Komanda, Mambasa, Mangina and Goma to address rumors and encourage participation and use of various response services, including contact tracing.[11-15]	Evaluating the disseminatio effectiveness of the FAQ do video Determining how news of e treatment may be used to g positive attitudes towards c Exploring the geographic sc response educational activi determine audience reach outbreak and preparedness

erception that Ebola does not exist, or that the existing Ebola epidemic is being exploited for commercial or political gain

VE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
eys[5, 16-19] questions were not asked elation to contact tracing, he survey on general Ebola showed that between a) and 54% (Karisimbi) of elieved that the Ebola t real. Among those who do at Ebola is real, between 9% and 62% (Mambasa) he epidemic had been political purposes, and 37% 55% (Goma) for financial tembo, 25% (n=230/961) of ated that they believe that exist. A greater proportion bt that the epidemic in North he epidemic was for financial gain" (85%, destabilize the region" (86%,	Interviews and Focus Groups[8,21] In Butembo and Katwa, doubting the existence of Ebola was a major theme in 19 of 34 key informant interviews and 4 of 9 focus groups. For others, however, the theme was slightly different, namely that the lack of 'belief' in the disease stems more from the stance that the Ebola epidemic is being used for financial purposes (but not that it does not exist). In Beni, the "community death" study revealed a perception in the community that local health authority workers are paid for each alert they issue and the "ETC refusal" study revealed that most participants questioned the existence of EVD. Studies in Beni and Butemo reveal community perception that health personnel may be motivated to report “false alarms” for Ebola because they may be financially compensated for the number of alerts they issue. This perception may be influenced by a general lack of awareness of Ebola symptoms, which leads to mistrust in Ebola case identification.	Several development projects have been launched to meet basic infrastructure needs (e.g. drinking water, flood damage prevention),[22-23] which serve to demonstrate to citizens that the government and international organizations are invested in their health and well-being. The response has offered new options for contact tracing to reduce visibility of the response in communities. Instead of daily visits, an intervention officer can stay with a family for the entire 21-day period, or the family can be moved to another location for duration of the 21-day follow-up.[24] A media message was created and aired on television with Congolese celebrity Dikembe Mutombo discussing the Ebola epidemic to reinforce that it is real.[25]	Evaluating the impact of th media message Conducting a formative eva message development and for communications that co connection between non-E development projects and response organizations’ inv improving the well-being o population Conducting a study to dete that influence belief in the the impact of belief or disb numbers and adoption of p practices

egative opinion of contact tracing (and surveillance) staff competence

VE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
eys[16-19] no had contact with aff indicated that the e not adequately informed the response in two health eni women) and 40.5% ess than 5% reported this tembo/Katwa and Goma.	Community Feedback[6-7] Across 12 health zones, 27% (n=247/914) of community feedback revealed concern regarding the competence of contact tracers. The highest rate was recorded in Butembo (55%) and the lowest in Katwa (18%). Interviews and Focus Groups[8] In 7 of the 34 interviews and 2 of the 9 focus groups conducted in Butembo and Katwa, participants expressed doubts about the quality and competence of the response agents, including their lack of self-confidence, communication of contradictory messages, and the fact that they are not health professionals.	Capacity-building activities are underway for contact tracing agents to improve technical and communication skills, including surveillance team training conducted in June 2019.[26] An FAQ document has been distributed to contact tracers and is used in training.[9] WHO developed a smart phone-based reporting system to increase speed, efficiency, and standardization of contact reporting and validation.[27] Intended outcomes include improved effectiveness of field staff and improved perception of staff competence.	Examining the variability in of competence by health zo identifying high-performing may serve as models Evaluating the disseminatio effectiveness of the FAQ do

egative opinion of response team staff as a whole

VE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
eys[16-19] 2% of those who had contact ce staff reported that the espectful or aggressive. This blem in Butembo/Katwa or 0% of the women surveyed community surveyed problem.	Interviews and Focus Groups[8] Negative perceptions of responding agents were evident in 17/34 interviews and 5/9 focus groups, including comments regarding belief that response staff were dangerous or cursed. In Butembo/Katwa, participants commented that the presence of RECO in the community was embarrassing.	To build relationships with the community, RCCE teams continue to organize engagement and awareness events including sporting events; radio station spots; conference debates; door-to-door outreach; reaching out women's associations, traditional healers, neighborhood leaders, and holding youth, corporate, and church events.[12-15] New options for families involved in contact tracing (see Barrier B "Mitigation Activities") may help to change attitudes towards responding agents.[24] The development of community outreach committees (Cellules d'Animation Communautaire [CACs]) may provide an outlet for specific issues with contact tracers.[13]	Exploring the geographic sc response educational activi determine audience reach outbreak and preparedness Enumerating and describin development and functioni

DISCUSSION

In summary, barriers to contact tracing are related to lack of information, skepticism about the epidemic and the response, and concerns about the capacity of contact tracers. The response has taken a number of important steps to address these concerns. For example, more automated systems (using smartphones) for collecting and reporting contact tracing data have been introduced,[27] as well as new options for contact tracing participants to participate in less publicly visible ways.[24] Efforts are underway to provide more training and orientation tools for contact tracers,[9] and the response has been active in educating the community about contact tracing. An evaluation of the dissemination and use of the FAQ document and video is recommended to identify whether there is a rationale for updating and expanding these tools. Disbelief of EVD and suspicion of the response are barriers to participation in the response in general (beyond simple contact tracing). A notable opportunity to increase confidence in response efforts, which could be further explored, is to publicize current efforts by international partners to support infrastructure development outside of the Ebola response (e.g. drinking water, flood prevention)[22-23] to demonstrate to citizens that the government and international organizations are invested in their health and well-being. In the future, more data should be collected on community responses to contact tracing to identify more sensitive indicators of the impact of response efforts.

TABLE 2. BARRIERS TO PARTICIPATION IN VACCINATION

Barrier A. Confusion regarding ring vaccination (including eligibility) and opposition to selective vaccination of individuals

QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	AD
CASS KAP Surveys[1-5] In a KAP survey in Katwa and Butembo, 66% of participants mentioned a lack of information on vaccination. Many refused the vaccine due to lack of information: 16% (women in Beni) to 72% (Katwa). Participants stated that a common reason for refusal of the vaccine may be a lack of clarity regarding who is supposed to be vaccinated (ranging from 20% in Butembo to 47% in Katwa), and approximately one-fifth of participants reported having questions about who is eligible for the vaccine (22% in Butembo, 23% in Katwa, 23% in Mambasa and 25% in Karisimbi). KAP Survey[6] A survey conducted in Beni, Butembo, Mangina and among displaced people (IDPs) in the Komanda camp revealed that 82% of participants agreed or strongly agreed that everyone should be vaccinated, not just Ebola contacts.	Community Feedback[7-9] The most common sentiment identified in community feedback comments was dissatisfaction with how the vaccination programs are run, with over 23,000 comments corresponding to this theme. There were also frequent expressions of suspicion and anger about what is perceived as selecting some people over others for vaccination. Example comments: ● "Why not vaccinate the entire population as was done with meningitis?" ● "Why isn't the EVD vaccine given door-to-door like other vaccines?" Focus Group[6] Key informants from Beni, Butembo, Mangina and IDPs in the Komanda camp reflect confusion and suspicion. "For example, they are refusing the vaccine to pregnant women, yet we know that pregnant women are always vaccinated to protect babies. We are asking if this policy is not a way to exterminate us."	The response developed an FAQ document including vaccination questions,[10] which is now used by vaccination teams for training and in the field. The RCCE and vaccination teams have developed three communication tools that explain and compare the Ebola vaccine to other vaccines, and have created and will promote a short video on vaccination.[11] In a few test areas (Lwemba in Biakato; Bingo in Mangina), geographic vaccination rather than ring vaccination is being piloted. The RCCE team has developed a communication strategy to explain geographic vaccination in these communities.[12] The RCCE team has organized numerous public awareness sessions, home visits and radio broadcasts on the importance of vaccination.[12] The RCCE team is engaging traditional healers in the response to provide vaccination and to promote ring vaccination, particularly in remote health areas.[13] Internews published the answers to an important community question in its Tulivyo Sikia Bulletin No. 2: "Why vaccinate only the population of Goma and deprive us of the Johnson & Johnson vaccine?"[14]	Eva im rec Str sub ne im co sci ap De an ac De we va pa ge

Barrier B. Belief that the vaccine is ineffective

QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	AD

KAP Survey[15-16] In Beni and Butembo, only 66% of participants said they believed Ebola vaccine is effective. Of those who would not accept the vaccine, 23% said it was because the vaccine does not work. In North Kivu, 75% of participants were aware of the Ebola vaccine but only 59% thought it protected against Ebola. CASS KAP Surveys[3] While a majority (56%-86%) of participants in the different health zones cite vaccination as a means of stopping transmission, this suggests that in some areas significant minorities do not see vaccines as such.	Community Feedback[7-9] Several comments related to doubts about the efficacy of the vaccine. Example comments: ● "The vaccine given is not effective in fighting against Ebola." (Butembo) ● "There is no effective medication or Ebola vaccine because even people who are vaccinated die of the Ebola virus." (Butembo) ● "Even people who already vaccinated start to die, so we do not want the vaccine anymore." (Katwa)	Please see Barrier A, " Promotion Activities." In addition to explaining the ring vaccination strategy, these educational activities can also serve to convey the message that the vaccine helps to prevent Ebola infection. In Goma, the RCCE and the vaccination teams developed a communication plan for the introduction of the new vaccine. This plan will address the benefits of the vaccine and the vaccination schedule.[17]	Ga cla ine
Barrier C. Fear of side effects			
QUANTITATIVE FINDINGS	**QUALITATIVE FINDINGS**	**PROMOTION ACTIVITIES**	**AD**
Published Surveys[15,18] In Beni and Butembo, 63% of participants stated that they would accept the Ebola vaccine. Of those who would not accept the vaccine, over 50% cited belief that the vaccine is unsafe, or poses risk or danger. CASS KAP Surveys[19-20] Approximately 22% reported fear of vaccination. Roughly 50% (Mambasa and Beni) to 65% (Bunia, Rwampara) of the healthcare workers surveyed thought that health staff might not be vaccinated for fear of side effects.	Community Feedback[7,9] Community feedback revealed suspicions about short and long-term side effects of vaccination, including general illness, disability (physical and mental), paralysis, and birth defects and infertility in men and women. Participants also expressed concern about the experimental status of the vaccine.	Please see Barrier A, "Promotion Activities." In addition to explaining the ring vaccination strategy, these educational activities also serve to convey the message that the vaccine helps to prevent Ebola infection. Internews published the answers to an important community question in its Tulivyo Sikia Bulletin No. 2: "Do both vaccines have side effects?"[14]	De usi alr fea Co exa un sid the vac pla
Barrier D. Fear that the vaccine transmits Ebola			
QUANTITATIVE FINDINGS	**QUALITATIVE FINDINGS**	**PROMOTION ACTIVITIES**	**AD**
CASS KAP Surveys[1-2] While the fear that vaccination might transmit the Ebola virus was reported with moderate to low frequency (20-26% of participants) in several regions the belief seemed to be more widespread in certain localities (Beni women-only survey, 47%; Mambasa, 61%).	Community Feedback[9] Community reactions claiming that the vaccine causes or spreads the Ebola virus have been identified in a number of health zones and persist over time. In some scenarios, the vaccine is seen as a means of deliberately spreading the Ebola virus, or the vaccine is used to exterminate the population (or specific minority groups).	Please see Barrier A, "Promotion Activities." In addition to explaining the ring vaccination strategy, these educational activities also serve to convey the message that the vaccine helps to prevent Ebola infection.	Exp co thi

DISCUSSION

When examining barriers to EVD vaccination, two competing concerns emerge: one is the lack of confidence in the vaccine (demonstrated by the belief that it is ineffective or fear of side effects), while the second is the sense of injustice associated with ring vaccination (since it involves selectively vaccinating only close contacts of suspected cases). The introduction of a new vaccine (Johnson & Johnson) in November 2019 (in preparation areas) that does not use a ring vaccination strategy, and the piloting of the administration of the first vaccine (Merck) using a geographical approach rather than a ring strategy (in limited areas), will likely change the dynamics around vaccine acceptance One potential barrier that was suggested by qualitative data but not corroborated with quantitative data was that eligible people were unable to get the vaccine for logistical reasons, either because they had to travel to receive the vaccine or because they were asked to pay for it. This merits further exploration. Additional research on vaccine acceptance will also shed light on how the introduction of a new vaccine and new implementation strategies affect perceptions and barriers to immunization.

TABLE 3. BARRIERS TO PARTICIPATION IN TRANSPORT TO THE EBOLA TREATMENT CENTER (ETC)

ef that there is a strong association between the ETC and death

FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
s[1-11] th zones, between 60-82% yiragongo being the only 6%) said that they would family member to go to ere suspected of having ey believe that people C die. es also had high 80%) of people reporting Mandima, Niyragongo, ugh variation in the way asked limit its	Community Feedback [12-13] Multiple health zones provided comments suggesting a belief that everyone who goes to the ETC dies. Example comments: ● “When those who are sick with Ebola virus are brought to the Ebola Treatment Center, they die, so there’s no point in us bringing them.” (Bunia) ● "Once at the ETC, the patient always dies." (Goma) CASS Interviews and Focus Groups[11,14] In all the focus groups, participants expressed the feeling that the ETC is a ‘place of death.’ Example comment: ● “What I know about the ETC it is a place where if you go, you cannot come back.”	The RCCE teams have organized events to engage the community, key leaders, and Ebola survivors to raise public awareness and increase acceptance of ETCs[15-17]. Two videos were created for dissemination in the community, one with a survivor's testimony[16] and another with messages on the use of ETCs for the general public.[17] The RCCE teams in Beni, Mambasa, Mangina and Goma organized public visits to ETCs to demystify the service and promote its use, and in Aloya (Mangina), they met with women's groups to increase participation in ETCs.[17-18] The response provided communicators with information describing a patient's journey, "Parcours du malade" (meaning “Patient Journey”) to share with the public.[19]	Assessing the geographic cov response activities designed fears of the ETC and perceive with death across the Ebola- to further understand percep the ETC Evaluating the distribution, u of the two videos and the “P malade” communication ma identify the extent to which address perceptions around

ception that Ebola does not exist, or that the existing Ebola epidemic is being exploited for commercial or political gain

FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
s[1-11] stions were not asked ation to contact tracing, survey on general ola showed that between and 54% (Karisimbi) of ved that the Ebola t real. Among those who at Ebola is real, between) and 62% (Mambasa) epidemic had been itical purposes, and 37% % (Goma) for financial [20] mbo, 25% (n=230/961) of d that they believe that xist. A greater proportion that the epidemic in North epidemic was r financial gain" (85%, stabilize the region" (86%,	Interviews and Focus Groups[11] 6 of the 11 focus groups in Lwemba, Butembo and Katwa and 19 of the 34 interviews had had the theme that Ebola does not exist, or that Ebola exists and response personnel are spreading it for profit. Example comment: ● "Ebola doesn't even exist. Once you get to the ETC, you inject patients with products that weaken them.” Most (n=9/16) of the individuals interviewed in Biakato, Bingo, Katanga and Lwemba questioned the existence of Ebola.	A media message was created and aired on television with a Congolese celebrity discussing the Ebola epidemic to reinforce that it is real.[21] Several development projects have been launched to meet basic infrastructure needs (e.g. drinking water, flood damage prevention)[22-23], which serve to demonstrate to citizens that the government and international organizations are invested in their health and well-being. In February-March 2019 there were efforts made across all agencies to reduce the visibility of response efforts in the community, including moving from cars to motorbikes as a form of transportation or having teams carpool together.[24]	Evaluating the impact of the media message on communi Conducting a formative evalu message development and p communications that convey connection between non-Eb development projects and El organizations’ investment in well-being of the population Exploring opportunities to in into the health system rathe addresssing Ebola as an inde problem

ef that ETC staff disregard other illnesses

FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES	ADDITIONAL OPPORTUN
s[1-11] Mambasa, 20%-26% of rted that worrying about er disease while at the hem from sending a family C.	Community Feedback[12-13] Although the percentages are relatively low in the surveys, there is a large body of qualitative evidence that reveals fear that other health problems are ignored at the ETC. Participants are concerned that when people are brought to the ETC for testing, their underlying illnesses may remain untreated while they wait, resulting in death. Sample comments: ● "At the ETC, the sick are abandoned. They are not given any medication. That's why patients die there even if they don't have Ebola.	The RCCE team produced a radio program on the testimonies and reintegration of a non-case released from the Bunia ETC.[25] UNICEF reports that the RCCE has organized visits and briefings on the ETC for the community, including explaining how the ETC works and tours to display what happens there.[26-27]	Exploring opportunities to in number of health facilities th triage processes, including fo test negative, to convey a hig attention and care for all pat regardless of illness Exploring opportunities to in into the health system rathe addresssing Ebola as an inde problem

	● "Why are patients dragged to the ETC to wait for lab results without being treated?"		
ef that care is provided only to patients known by ETC staff			
FINDINGS	**QUALITATIVE FINDINGS**	**PROMOTION ACTIVITIES**	**ADDITIONAL OPPORTUN**
[1-11] ne-fifth of participants in and Mandima (20%) said ot encourage a family he ETC if they were ng Ebola because they is only given to people by ETC staff. In the other s than 13% of participants	Community Feedback[12,27] Some community members expressed perceptions of preferential treatment for people who are well-connected. Examples of comments: ● "In the Ebola treatment center, people are treated according to whether they are known; otherwise, they die." ● "We have noticed that at the ETC it's all about who you know. When you are known by the healthcare workers, you are well cared for and cured.	The RCCE teams have been working on engaging the community by recruiting locally and including influential women, religious leaders and traditional healers in the response and in the community outreach units (Cellule d'Animation Communautaire [CACs]).[16,29] This helps develop local buy-in and build trust. ETCs are employing vaccinated Ebola survivors to help provide care for patients, and medical students trained in infection prevention and control are placed in high-risk health facilities in their home communities.[30-31] Ideally, increasing the number of caregivers from the community will increase trust in the ETC.	Exploring this barrier further more robust quantitative dat analyzing geographic variatio

DISCUSSION

The principal barriers to willingness to go to an ETC are: (1) a perception that the ETC leads to death; and (2) a general skepticism about the reality of the Ebola epidemic. Although several other themes related to people's perceptions and experiences with ETCs emerged in the community responses, few of these were validated by quantitative data. The following two themes had some quantitative results to support them, but frequencies were not very high (not higher than 26%): "Belief that ETC staff disregard other illnesses" and "Belief that care is provided only to patients known by ETC staff." As noted above, response communication teams have carried out several activities to change beliefs around ETCs, to address concerns about the Ebola response, and to build confidence in the health system. However, it is difficult to fully assess the extent to which this activities are addressing these barriers without greater detail about the geographic scope and strategy of community education activities.

TABLE 4. BARRIERS TO PARTICIPATION IN SAFE AND DIGNIFIED BURIAL (SDB)

Barrier A. Suspicion of burial practices where the body is obscured		
QUANTITATIVE FINDINGS	**QUALITATIVE FINDINGS**	**PROMOTION ACTIVITIES**
HHI Survey[1] In Beni and Butembo, only 4% found it acceptable to have the body obscured during the ceremony.	**Community Feedback[2-3]** Community feedback revealed suspicion around burials where the body is obscured in a body bag or an opaque coffin, particularly with regard to mutilation of the body. Example comments: ● "We want the bodies to be shown to the community after they are put in the body bag to confirm that it is the same person." ● "You cut off people's organs during the safe and dignified burial." **SSHAP synthesis,[4] CASS data synthesis,[5] and Published Conflict Scan[6]** Media monitoring uncovered rumors in the local media regarding theft and mutilation of bodies and pre-digging of graves (prohibited by Nande culture). Additionally, a conflict scan using focus groups and key interviews of 218 people found that people had the belief that the soul cannot escape the body bag and find rest.	Transparent body bags were introduced in June 2019, and by August 2019 at least one funeral service provider in each zone was using them.[7]
Barrier B. Lack of information on how safe and dignified burial is conducted		
QUANTITATIVE FINDINGS	**QUALITATIVE FINDINGS**	**PROMOTION ACTIVITIES**

CASS KAP Surveys[8-14] Across seven health zones, about two-thirds of people in Katwa and Beni listed SDBs as the best way to control Ebola. In other zones less than one third mentioned SDB as a way to control EVD (lowest: 2% in Goma). Some participants had questions about SDB in general (highest in Butembo (43%). One frequent question was about where people who die from Ebola are buried (35% in Katwa, 25% in Butembo, 19% in Mambasa, and <8% in the other health zones.)	**Community Feedback** [2-3] Questions from the community about how safe and dignified burial is conducted and the rationale for it were one of the top three community feedback themes among SDB comments from six health zones. Example comments: ● "Why do you want to bury all dead bodies, even in a negative case?" ● "The burial you perform, it happens when and how?" ● "People never saw where you bury people with Ebola, where do you take them?"	The RCCE teams have organized awareness campaigns, sports events and home visits, and engaged with community radio stations and youth and women's associations to increase acceptance of the response.[15] The RCCE team has also been active in the area of education and training, with more than 23,000 homes visited. [16] The RCCE team is undertaking a series of activities to increase public understanding of SDB and the swab collection process.[15-16] In Beni, Mangina, and Mambasa, the response uses a video kit that explains safe and dignified burial and the RCCE team is working on facilitating and distribution of the video kit to all health zones.[17]

Barrier C. Belief that safe and dignified burial is not culturally acceptable or does not respect customs

QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES
KAP Survey[1,4] Across health zones, only 25% of participants reported that they would accept that medical staff dress the deceased instead of a family member for a funeral; 9% would accept that the body remain in a medical facility before being buried rather than at home; and 2% would accept having medical personnel bury the body. In Beni and Butembo, only 35% of participants found it acceptable to proceed with the burial without waiting for relatives to travel from far away. CASS KAP Survey[8-14] In 5 of the 7 health zones, more than 50% accepted the idea that someone from outside the family could perform burial.	Community Feedback [2-3] Some community feedback indicated perceptions that the response shows a lack of respect for the deceased. Example comments: ● "What dignity do you show when you leave corpses in the sun?" ● "The way you bury the dead of Ebola does not relieve the population; look for other methods." Published Mixed Methods Study[18] Focus group participants from Beni, Butembo, and Mangina, and IDPs in Komanda camp expressed that seeing an Ebola patient after death was important to the family. Example comment: ● "Our culture demands that we say goodbye to the one that goes ahead of us to the beyond. It's a powerful moment for us." SSHAP Synthesis,[4] CASS Data Synthesis,[5] Published Conflict Scan[6] Media monitoring found claims that SDB teams were aggressive and did not communicate with grieving families. CASS analysis cited similar issues. The conflict scan showed concerns about certain cultural practices, such as pre-digging of a grave (prohibited by Nande culture).	The RCCE teams have been working on engaging the community by recruiting locally and including influential women, religious leaders and traditional healers in the response and in the community outreach units (Cellule d'Animation Communautaire [CACs]).[17,19] The WHO updated guidelines in 2017 that include specific burial practice adaptations for Muslims. For example, these adaptations include spraying perfume instead of washing the body.[20]

Barrier D. Lack of understanding around how the body remains infectious after death from EVD

QUANTITATIVE FINDINGS	QUALITATIVE FINDINGS	PROMOTION ACTIVITIES
KAP Survey[1,4] Across health zones, only 56% report knowing that Ebola can be contracted by touching dead people, and only 39% reported avoiding the body of someone who has recently died of Ebola (high of 61% in North Kivu). CASS KAP Surveys[8-14] In four of eight health zones, less than 50% believed that Ebola is transmitted by touching the bodies (range by health zone: 20%- 95%). Published Mixed Methods Study[18]	Community Feedback[2-3] Some community members have reported that they touched the body of a deceased Ebola patient and did not contract Ebola. Based on this experience, they concluded that Ebola is not real. Example comments: ● "Ebola is a lie: we knew a positive case; we touched the patient and his dead body afterward, and yet we are well; we refused the vaccine." ● "Awareness is good, but why aren't any Red Cross volunteers dying from Ebola, given the high number of corpses they bury?"	Please see Barriers B and C, "Promotion Activities." These promotion activities also serve to educate the community around the body remaining infectious after death. In Bunia, after a dialogue facilitated by the RCCE team in collaboration with the surveillance and IPC staff, 50 members of car and motorbike taxi drivers' associations of Bunia and Rwampara committed to stop transporting dead bodies (infected or not) without a medical document.[21]

A study in Beni, Butembo, Mangina, and IDPs in Komanda found that only 4% would touch the body if a family member died.		

DISCUSSION

Early in the response, SDB leadership recognized the importance of the body being visible and identifiable to loved ones during burial, and they responded by introducing partially transparent body bags. It is not clear whether these bags have been made available for all burials, but the predominance of the concern about seeing the body suggests that this may be an effective solution. While community feedback does not show a strong reaction to the use of clear body bags,[7] future collection of community feedback regarding satisfaction with the burial process should provide more specific and actionable feedback. Other barriers included not having enough information about SDB, and fears that cultural traditions are not respected. Response activities include community education, obtaining agreement before proceeding with safe and dignified burial, and adjusting procedures to accommodate family desires. Without more specific information on the nature and scope of these efforts, it is difficult to assess how well they are able to address these barrier. It is notable that survey responses from one health zone to the next are divergent, which suggests that community engagement and SDB activities are more effective in some areas than others. Further inquiry should be conducted to identify success stories, and strategies could be replicated in other areas.

References: Table 1

1. CASS. Analysis of Knowledge, Attitude, and Practice Survey of Community Members on Ebola: Butembo and Katwa. Presented on June 26, 2019.
2. CASS. Analysis of Knowledge, Attitude, and Practices Women, Beni, June 28 – July 3. Presented July 2019.
3 CASS. Analysis of the Rapid Study of Knowledge, Attitudes, and Practices, Women Contacted of the Ebola Response, Bunia, Rwanpara, July 15 – 22, 2019. Presented August 19, 2019.
4. CASS. Analysis of the Health Knowledge, Attitudes and Practices (KAP) Study in Goma, August 15 – 18, 2019. Presented on September 15, 2019.
5. CASS. Presentation of the Analyses of the Rapid Study on Community Knowledge, Perceptions, and Practices Related to Ebola: Mambasa. Presented on October 8, 2019
6. International Federation of Red Cross and Red Crescent Societies IFRC Community Feedback to Inform Ebola Response Efforts. Community Perspectives on Contact Tracing, August 2018—July 2019. Unpublished report, September 17, 2019.
7. International Federation of Red Cross and Red Crescent Societies. Regional Commission. Ebola response in North Kivu in the DRC IFRC Community Feedback System. Presented March 24, 2019.
8. CASS. Quick Study: Barriers & Motivators of Participation in Listing and Tracking of Contacts. Unpublished report. June 3, 2019.
9. International Federation of Red Cross and Red Crescent Societies and Centers for Disease Control and Prevention Social and Behavioral Science Taskforce. Red Cross-CDC FAQ document for contact tracers to use in the field for answering questions.
10. Medical Aid Films. "Ebola – Agents de suivi." *YouTube*, uploaded by Medical Aid Films – Films for Life, May 12, 2015, https://www.youtube.com/watch?v=TTQiEDBmQJA
11. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, August 12, 2019.
12. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, August 19, 2019
13. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, November 24, 2019.
14. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, December 15, 2019.
15. CASS. Monito Recommendations. Follow up on Recommendations. Version accessed: January 13, 2020.
16. CASS. Analysis of Mambasa Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
17. CASS. Analysis of Goma Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
18. CASS. Analysis of Butembo/Katwa Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 11, 2019.
19. CASS. Analysis of Beni (Women) Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
20. Vinck P, Pham PM, Bindu KK, Bedford J, Nilles EJ. Institutional trust and misinformation in the response to the 2018–19 Ebola outbreak in North Kivu, DR Congo: a population-based survey. Lancet Infect Dis 2019; 19: 529–36.
21. CASS. Quick Study of the Reluctance/Refusal to go to the ETC, Madima, Mabalako, Butembo and Katwa. Presented on September 18, 2019.
22. USAID. Democratic Republic of the Congo – Complex Emergency. Fact Sheet#1, Fiscal Year 2020, December 2, 2019: https://www.usaid.gov/sites/default/files/documents/1866/drc_ce_fs01_12-02-2019.pdf
23. USAID Country Development Cooperation Strategy: Democratic Republic of the Congo, 2014–2021. https://www.usaid.gov/sites/default/files/documents/1860/Democratic_Republic_of_Congo_CDCS_2014-2021updated2.pdf
24. Reported from the field at the CDC Incident Manager update, 01/25/2020 .
25. CDC. Dikembe Mutombo Ebola PSA, June 20, 2019: https://www.cdc.gov/vhf/ebola/outbreaks/drc/Dikembe-Mutombo-Ebola-PSA.html
26. Correspondence with Simone Carter, UNICEF. 04/01/2020.
27. WHO Africa. Speeding up detection to slow down Ebola: Smartphone app is game-changer for contact tracing in hotspots in the Democratic Republic of the Congo. https://www.afro.who.int/news/speeding-detection-slow-down-ebola-smartphone-app-game-changer-contact-tracing-hotspots

References: Table 2

1. CASS. Analysis of the Rapid Study of Knowledge, Attitudes, and Practices, Women Contacted of the Ebola Response, Bunia, Rwanpara, July 15–22, 2019. Presented August 19, 2019.
2. CASS. Analysis of Knowledge, Attitude, and Practice Survey of Community Members on Ebola: Butembo and Katwa. Presented on June 26, 2019.
3. CASS. Presentation of the Analyses of the Rapid Study on Community Knowledge, Perceptions, and Practices Related to Ebola: Mabalako and Mandima, April 20–May 1, 2019.
4. CASS. Presentation of the Analyses of the Rapid Study on Community Knowledge, Perceptions, and Practices Related to Ebola: Mambasa. Presented on October 8, 2019.
5. CASS. Integrated analysis: recommendations for the rapid response teams in the new zones of epidemic. Presented on November 13, 2019.
6. Masumbuko Claude K, Underschultz J, Hawkes MT Social resistance drives persistent transmission of Ebola virus disease in Eastern Democratic Republic of Congo: A mixed methods study. PLoS ONE, 2019, 14(9): e0223104. https://doi.org/10.1371/journal.pone.0223104
7. International Federation of Red Cross and Red Crescent Societies. Community Feedback to Inform Ebola Response Efforts. Community Perspectives on the Ebola Ring Vaccination Campaign. Unpublished report, June 17, 2019.
8. Social Science in Humanitarian Action Platform. Data Synthesis Brief, June 11, 2019.
9. International Federation of Red Cross and Red Crescent Societies. Red Cross Community Feedback to Inform Ebola Response Efforts. Refusals and reluctance towards: contact tracing and monitoring; Ebola Treatment Centers; and Ebola vaccination. Unpublished report, May 28, 2019.
10. International Federation of Red Cross and Red Crescent Societies. Red Cross-CDC FAQ document for contact tracers to use in the field for answering questions.
11. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, November 24, 2019.
12. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, December 15, 2019.
13. CASS. Recommandations monitito. Follow up on Recommendations. Version accessed: January 13, 2020.
14. Internews Tulivyo Sikia #2: 26 Dec 2019
15. Vinck P, Pham PM, Bindu KK, Bedford J, Nilles EJ. Institutional trust and misinformation in the response to the 2018–19 Ebola outbreak in North Kivu, DR Congo: a population-based survey. Lancet Infect Dis 2019; 19: 529–36.
16. Social Science in Humanitarian Action Platform. Social science and behavioural data compilation (#4), Ebola outbreak eastern DRC, June-August 2019. Data Synthesis Report, September 2019.
17. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, November 10, 2019.
18. Harvard Humanitarian Initiative. Voices from Congo, Peacebuilding and Reconstruction Polls. Poll 18: April 20 – May 10, 2019.
19. CASS. Key Findings from UNICEF KAP Survey of Ebola Healthcare Workers in Beni, Butembo, and Katwa. Unpublished Report, June 30, 2019.
20. CASS. Quick Study on Knowledge, Attitude, and Practices related to EVD. Health Personnel, Beni with comparisons of Butembo. Presented June 2019.

References: Table 3

1. CASS. Key Findings from KAP Survey of Ebola Healthcare Workers in Beni, Butembo, and Katwa. Special analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, June 30, 2019.
2. CASS. Analysis of Knowledge, Attitude, and Practice Survey of Community Members on Ebola: Butembo and Katwa. Presented on June 26, 2019.

3. CASS. Analysis of Beni (Women) Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
4. CASS. Analysis of Knowledge, Attitude, and Practices Women, Beni, June 28 – July 3. Presented July 2019.
5. CASS. Analysis of Butembo/Katwa Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 11, 2019.
6. CASS. Analysis of the Rapid Study of Knowledge, Attitudes, and Practices, Women Contacted of the Ebola Response, Bunia, Rwanpara, July 15 – 22, 2019. Presented August 19, 2019.
7. CASS. Analysis of Goma Knowledge, Attitude, and Practice (KAP) Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
8. CASS. Analysis of the Health Knowledge, Attitudes and Practices (KAP) Study in Goma, August 15 – 18, 2019. Presented on September 15, 2019.
9. CASS. Analysis of Mambasa Knowledge, Attitude, and Practice Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
10. CASS. Presentation of the Analyses of the Rapid Study on Community Knowledge, Perceptions, and Practices Related to Ebola: Mambasa. Presented on October 8, 2019
11. CASS. Quick Study of the Reluctance/Refusal to go to the ETC, Madima, Mabalako, Butembo and Katwa. Presented on September 18, 2019.
12. International Federation of Red Cross and Red Crescent Societies. Red Cross Community Feedback to Inform Ebola Response Efforts. Refusals and reluctance towards: contact tracing and monitoring; Ebola Treatment Centers; and Ebola vaccination. Unpublished report, May 28, 2019.
13. International Federation of Red Cross and Red Crescent Societies. Red Cross Community Feedback to Inform Ebola Response Efforts. Community Perceptions of Ownership and Involvement in the Ebola Response. Unpublished report, June 20, 2019.
14. Social Science in Humanitarian Action Platform. Social science and behavioural data compilation (#4), Ebola outbreak eastern DRC, June-August 2019. Data Synthesis Report, September 2019.
15. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, December 15, 2019.
16. CASS. Monito Recommendations. Follow up on Recommendations. Version accessed: January 13, 2020.
17. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, November 10, 2019.
18. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, October 27, 2019.
19. Correspondence with Vivienne Walz, CDC. January 15, 2020.
20. Vinck P, Pham PM, Bindu KK, Bedford J, Nilles EJ. Institutional trust and misinformation in the response to the 2018–19 Ebola outbreak in North Kivu, DR Congo: a population-based survey. Lancet Infect Dis 2019; 19: 529–36.
21. CDC. Dikembe Mutombo Ebola PSA, June 20, 2019: https://www.cdc.gov/vhf/ebola/outbreaks/drc/Dikembe-Mutombo-Ebola-PSA.html
22. USAID. Democratic Republic of the Congo – Complex Emergency. Fact Sheet#1, Fiscal Year 2020, December 2, 2019: https://www.usaid.gov/sites/default/files/documents/1866/drc_ce_fs01_12-02-2019.pdf
23. USAID Country Development Cooperation Strategy: Democratic Republic of the Congo, 2014–2021. https://www.usaid.gov/sites/default/files/documents/1860/Democratic_Republic_of_Congo_CDCS_2014-2021updated2.pdf
24. Correspondence with Simone Carter, UNICEF. 04/01/2020.
25. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, December 8, 2019.
26. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, November 24, 2019.
27. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, July 7, 2019.
28. Social Science in Humanitarian Action Platform. Politics, factions and violence: listening to local voices on Ebola. Local media update #3 (February-April 2019). Brief, May 21, 2019.
29. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, October 13, 2019.
30. Daily Mail. DR Congo Ebola survivors play crucial role helping victims of virus. Article published September 20, 2019. Obtained from Ebola in the Media, September 9, 2019: https://www.dailymail.co.uk/wires/afp/article-7486109/DR-Congo-Ebola-survivors-play-crucial-role-helping-victims-virus.html
31. APO Group. From one Ebola front line to another in the Democratic Republic of the Congo: Dr Didier Mwesha, WHO Infection Prevention and Control Expert. Article published October 10, 2019. Obtained from Ebola in the Media, October 11, 2019: https://www.africa-newsroom.com/press/from-one-ebola-front-line-to-another-in-the-democratic-republic-of-the-congo-dr-didier-mwesha-who-infection-prevention-and-control-expert?lang=en

References: Table 4

1. Vinck P, Pham PN, Makoond A, Zibika JP, Nilles E. Harvard Humanitarian Initiative. Rapid Ebola Survey. Unpublished Report, October 2018.
2. International Federation of Red Cross and Red Crescent Societies. IFRC Community Feedback to Inform Ebola Response Efforts. Community Perspectives on Safe and Dignified Burials. Unpublished report, July 12, 2019.
3. International Federation of Red Cross and Red Crescent Societies. Ebola response in North Kivu in the DRC IFRC Community Feedback System. Presented March 2019.
4. Social Science in Humanitarian Action Platform. Social science and behavioural data compilation (#4), Ebola outbreak eastern DRC, June-August 2019. Data Synthesis Report, September 2019.
5. CASS. Information Brief: Social Sciences Research Group – Ebola. Funeral Rites and Burials.
6. Mugula P and Ngaboyeka D. Conflict Scan Tupone Wote Pamjoa (Guerissons Ensemble dans l'est de la RDC), Butembo, North Kivu. USAID Search for Common Ground, Conflict Scan Report, June 2019.
7. Correspondence with International Federation of Red Cross and Red Crescent Societies. January 24, 2020.
8. CASS. Key Findings from KAP Survey of Ebola Healthcare Workers in Beni, Butembo, and Katwa. Special analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, June 30, 2019.
9. CASS. Analysis of Butembo/Katwa Knowledge, Attitude, and Practice (KAP) Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 11, 2019.
10. CASS. Analysis of Mambasa Knowledge, Attitude, and Practice (KAP) Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
11. CASS. Analysis of Beni (Women) Knowledge, Attitude, and Practice (KAP) Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
12. CASS. Analysis of Goma Knowledge, Attitude, and Practice (KAP) Survey. Special Analysis by Centers for Disease Control and Prevention Social and Behavioral Science Taskforce, October 15, 2019.
13. CASS. Analysis of Knowledge, Attitude, and Practice Survey of Community Members on Ebola: Butembo and Katwa. Presented on June 26, 2019.
14. CASS. Analysis of the Rapid Study of Knowledge, Attitudes, and Practices, Women Contacted of the Ebola Response, Bunia, Rwampara, July 15 – 22, 2019. Presented August 19, 2019.
15. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, December 15, 2019.
16. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, December 8, 2019.
17. CASS. Monito Recommendations. Follow up on Recommendations. Version accessed: January 13, 2020.

18. Claude KM, Underschultz J, Hawkes MT Social resistance drives persistent transmission of Ebola virus disease in Eastern Democratic Republic of Congo: A mixed methods study. PLoS ONE 2019;14(9): e0223104.
19. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, October 13, 2019.
20. WHO. How to conduct safe and dignified burial of a patient who has died from Ebola or Marburg. WHO Reference number WHO/EVD/Guidance/Burials/14.2. Guidelines October 2017. Available at https://www.who.int/mediacentre/news/notes/2014/ebola-burial-protocol/en/
21. UNICEF. Democratic Republic of the Congo, North Kivu and Ituri. Ebola Situation Report, November 10, 2019.
International Federation of Red Cross (IFRC). Safe and Dignified Burial data. Analysis by Centers Disease Control and Prevention Epi Team, January 20, 2020.

Authors and Acknowledgements

This synthesis was created by Giulia Earle-Richardson, Lindsay Tompkins, Linda Vo, Vishakha Ramakrishnan, Christine Prue, Simone Carter (with support from UNICEF and CASS team including Jessica Petz, Sonya Sagan, Pia Huq and Francklin Soung Brice), Ombretta Baggio, Eva Erlach, (with support from IFRC and Red Cross staff Cheick Camara and Lucia Robles) and Raoul Komanda, lead of the DRC Ebola Response Risk Communication and Community Engagement task force. Editorial and scientific assistance was provided by Amber Robinson, Kate Meehan, James Fuller, Beth Ervin, Marie Killberby, Sean Browning, Weiming Zhu, Daiva Yee, Molly Kurnit, and Leslie Ross.

The collection and analysis of the unpublished CASS KAP surveys in the DRC were conducted under the coordination and leadership of the Ministry of Health, validated by the coordinator Professor Steve Ahuka and coordinator Matthias Mossoko. At the field level, each study was signed off by the leads of the sub-coordinations. The CASS team is operationally managed by Simone Carter of UNICEF and includes 18 local researchers in Beni and Butembo as well as national and international teams. For the full team list, please consult the online link here: https://docs.google.com/spreadsheets/d/1e69Ip9eEudu9UIW7XXBs4gXXQL5Iu_dwGRg7rhdCKac/edit#gid=1681762368

The unpublished Red Cross/IFRC community feedback data were collected by Red Cross volunteers throughout eastern DRC, compiled and coded by Red Cross and IFRC staff, under the direction of Cheick Camara and Lucia Robles, and with the support of IFRC senior community engagement advisers Ombretta Baggio and Eva Erlach, and with the assistance of CDC health scientist Vivienne Walz.