STOP EBOLA à Rinangoma

We need to talk

Effective Ebola risk communication requires respect and transparency and remains as vital as ever

An assessment of changing communication needs and preferences in Beni, North Kivu

December 2019



Contents

Summary: what you absolutely need to know
We discussed communication needs and preferences in Beni7
Nande and Lingala are important languages to reach people who are not fluent in Swahili or French9
Key terms are still misunderstood and need to be translated and explained consistently
People have legitimate questions and need detailed and up-to-date answers in plain language
Communication formats must adapt to people's preferences and allow them to engage
What this means for your program41
TWB can help43
Acknowledgements44

Summary: what you absolutely need to know

In the second year of the current Ebola outbreak, effective risk communication remains as vital as ever. A Translators without Borders (TWB) study in Beni found that health communicators need more support to answer communities' questions in a way people understand. Communicators specifically lack support on language, content, and communication methods. The findings from Beni, in North Kivu Province, are relevant for the wider Ebola response in the Democratic Republic of Congo (DRC).

Interviews with health communicators and residents in September 2019 found that language barriers impede understanding of critical information on Ebola. Information in French and Swahili does not reach everyone. People misunderstand seemingly simple medical words in French. Swahili is best understood in the version local to Beni. while women and older people in the Beni area need information in localized Nande. Military personnel and their families need information in Lingala. To effectively communicate about Ebola, information needs to be relayed in all four languages.

The use of technical terminology presents its own language barrier. Key terms related to Ebola are in French and are not consistently translated. Health communicators themselves misunderstand them. Study participants explained that some words related to the outbreak are socially and culturally unacceptable. People consider those words harsh and offensive, especially words they associate with death. As a result, many people are reluctant to use those words. Health communicators replace them with their own euphemistic explanations. These alternatives can be inconsistent and vague, potentially leading to misunderstandings. Health communicators need support to translate Ebola-related terms in a socially acceptable and consistent way.

The content of the information provided is also problematic. Current messages on Ebola offer only basic information and instructions. They do not provide information that will help people to better understand why and how the prevention and treatment of Ebola works.

People's questions have evolved with the dynamics of the outbreak and changes in the response strategy. Study participants asked for complex and transparent information in a language and style that is familiar to them. They want in-depth explanations that relate to the latest developments. Yet health communicators lack communication tools and training adapted to these developments, and struggle to provide clear and consistent answers. The resulting misunderstandings and contradictions confuse people, and the lack of detailed explanations creates further doubt and frustration. Health communicators need detailed and regularly updated information in plain language to respond satisfactorily to people's questions.

Lastly, the study identified ways of making communication on Ebola more effective. People place more trust in information they receive in face-to-face communication. Community meetings, door-to-door, and educational talks are the preferred channels of communication. These give people the possibility to ask questions. Women in particular prefer to receive information from someone they know and trust. Local health communicators who are aware of cultural sensitivities around language and dress can relay information more effectively.

Printed materials can support inperson communication but these are not sufficiently available and lack detail. The images used are not selfexplanatory and can be confusing. The choice of colors also affects people's interpretation of the message. Study participants asked for extensive brochures covering all aspects of Ebola chronologically, with well illustrated, numbered images, and explanations in Swahili, Nande, Lingala and French.

In Beni and across the affected area, health communicators need more support to provide plainly worded, upto-date information in local languages. People need answers to their legitimate questions, in plain and accessible language, in formats that enable them to engage, and from people they trust.





We discussed communication needs and preferences in Beni

This qualitative study evaluates the challenges of communicating about Ebola in the town of Beni, North Kivu. With its approximately 250,000 residents, Beni has been one of the towns hardest hit by the epidemic declared in August 2018.

We talked to 205 individuals about language dynamics in the response, comprehension of Ebola-specific terminology, and sociolinguistic sensitivities around health. We visited nine health facilities in eight health areas (aires de santé) in Beni health zone and conducted structured ethnographic observations at each health facility. We talked to health workers, drop-in patients, and residents of the respective health areas. We also talked to health communicators, community outreach workers (*relais* communautaires). NGO field staff. volunteers, and program managers involved in the Ebola response. Throughout this report we use the term "health communicators" to refer to all health workers, health communicators, community outreach workers, NGO field staff and volunteers.

We conducted 25 focus group discussions. Ten groups focused on comprehension of existing Ebola risk communication materials and messages. We also conducted 20 open and semi-structured interviews. Field work took place between September 9 and 21, 2019. We conducted separate discussions with health workers, male residents, and female residents. We used a non-probabilistic purposive sampling method. To assure an even representation of women and men of different age groups, we applied a predetermined gender and age quota (34-18 years, 51-35 years, and over 52 years). Focus groups with residents were divided by age and gender.

We translated study tools into local Swahili and prepared study assistants for further translation into local languages. However, interview and focus group participants preferred to talk in Swahili. In focus group discussions the research team occasionally made use of Nande. Where possible, we recorded interactions through a combination of handwritten notes and voice recordings. These were later translated and transcribed into Swahili and French. Qualitative data was then cleaned, processed, and analyzed.

The team comprised six study assistants from Beni, aged 25 to 56, who were all fluent in French, Swahili and Nande. Some members of the team also spoke other local languages. Study assistants participated in a one-day training and a one-day pilot.

Limitations

Our study focuses on the town of Beni and is not representative of the wider Beni Territory, including more rural areas. The sample is statistically unrepresentative. However, we triangulated our results with the results from other studies conducted by the Social Science Analysis Cell (CASS) to assure coherence. Our sample did not include children and people with special needs.



Nande and Lingala are important languages to reach people who are not fluent in Swahili or French

Localized Swahili, Congolese French, the Nande of Beni, and Lingala are the four most spoken languages in Beni. Localized Swahili serves as the lingua franca and is spoken by most people. Currently, all written communication material used in the Ebola response is in either French or Swahili. To effectively communicate with the residents of Beni about Ebola, communication materials need to be available in all four languages.

"We have already received information, but we haven't really understood it yet, because we don't understand each other. We do not speak the same language as those who come [to talk] to us."

Female resident of Butsili, Beni

"The sensitization teams must consist of at least four people, because you will meet different categories of people who speak different languages. This one speaks French, the other Swahili, Nande, Lingala. That can really help, because there are many ethnic groups here."

Female resident of Mabakanga, Beni

Women and older generations need information in localized Nande

Many people in Beni speak a localized version of Nande - the Nande of Beni. Despite widespread use of Swahili, Nande remains important, particularly for women and older generations. Health communicators reported that they mix Swahili and Nande in consultations and face-to-face communications. Focus group participants repeatedly advocated for communication materials also to be available in Nande.

"For Ebola, we need [materials] even in Nande, the local language, so that if we give a flyer to a grandmother she will understand too."

Male pharmacist, Kanzuli, Beni

To communicate effectively with women and older people in Nande, it is important to use the localized version of Nande. The Nande of Beni Territory is very different from the Nande spoken in Butembo and Lubero Territories. Inhabitants of Beni refer to the Nande spoken in Butembo as "complicated Nande" and have difficulties understanding it. The Nande spoken in Beni borrows many words from Swahili, in what inhabitants of Beni interpret as a more modern version of Nande.

To say "I have stomach pain" in Nande, a Butembo speaker would say *Nikwire enda*, whereas a Beni speaker would say *Enda yayi ikaluma*. The phrase "There is a medicine against Ebola" in Butembo Nande translates to *Ine mivalio y'Ebola*, whereas in Beni Nande it translates to *Ine dawa enya Ebola*.

"When I'm among women, I talk a lot more in Swahili. But I mix it with Nande because there are several women who understand Nande better. But as the ethnic groups are mixed, Swahili comes first, Nande comes after."

Female communicator, Tamende, Beni

It is common practice in Beni to agree on a shared language, usually Swahili, before starting to talk. Local languages are therefore not commonly used in public, but mostly spoken within the family and among people who know each other. Due to the restricted use, speaking in Nande and other local languages implies intimacy, closeness, and trustworthiness. A message delivered in the Nande of Beni is considered more credible and reliable. This is also linked to the perception that a native speaker is more trustworthy than an outsider. "I much prefer mother tongue to get advice. Even if you speak Swahili, when it comes to giving advice, someone will speak to you in his language. That means you pay attention, because if he's speaking his own language, it must be serious."

Male resident of Tamende, Beni

Speaking in a local language that others don't understand is considered impolite and is often interpreted as an insult if one doesn't know the speaker. Therefore, despite the linguistic diversity in Beni, other local languages are rarely heard in public. But this does not imply that speakers of other languages are all fluent in Swahili. Speakers of languages like Mbuba or Mbuti often encounter language barriers.

"For the Bambuba, [it's best] if it's possible to have a person who speaks Mbuba, because they also have difficulty speaking Swahili or Nande. But then you have to know if you will be understood when you speak Mbuba. Same with Mbuti, so that the Pygmies understand the basic message." Lingala is an important language of communication for military personnel and their families

"Yesterday, there was a soldier who had an accident. The consulting doctor didn't know Lingala, and the soldier didn't know either Swahili or French. It was hard to get him to understand that we were just transferring him to the general hospital for treatment, not to the Ebola treatment center."

Doctor, Mandrandele, Beni

Lingala is one of the national languages of Congo and is spoken across large sections of the country. In Beni, it is particularly military personnel and their families stationed in the city who speak Lingala. They often don't speak Swahili or French and rely on information in Lingala. Providing them with detailed and accurate health information can therefore be difficult. Health centers and clinics often have at least one staff member who can interpret into Lingala. However other health communicators usually work only in pairs and may not be able to communicate about Ebola in Lingala.

Female resident of Tamende, Beni

"If we do not understand each other, I look for an interpreter, but he will not do the full translation of the symptoms. Really a lot of soldiers live in this area of Boikene."

Community health worker, Boikene, Beni

The choice of the right language to communicate with communities must include criteria that go beyond knowledge and literacy. The use of Lingala in the first months of the Ebola response was criticized as one of the main reasons why people avoided Ebola response teams. Lingala is a stigmatized language associated with the massacres which took place in previous years, and evokes memories of terror among Beni residents.

"We are afraid of Lingala in Beni town. Those who speak Lingala, we say they come to butcher us."

Laboratory technician, Mandrandele, Beni Another often overlooked reason for the unpopularity of Lingala is its tone. For Nande speakers, Lingala is a harsh language that sounds aggressive and rude. So when outsiders from other parts of the country spoke in Lingala, local Beni inhabitants felt they were being reprimanded in a language they did not fully understand. In a life or death context, this was experienced as immense disrespect.

"Lingala is a rude language. So, you meet a person, to talk to you he shouts "Yoo!!!" (you). When you talk like that to a patient, you can scare her and how can she answer?"

Female resident, Mandrandele, Beni

Speaking to non-Lingala speakers in that language is counter-productive. But Lingala speakers need information in their language.

Health information in French is poorly understood and frustrates the patient

Beni residents misunderstand seemingly simple medical terms in French, like "allergic", "virus" or "molecule." In the Ebola context, the use of medical terms in a language that is not accurately understood prompts immediate distrust among patients. Many patients fear that health workers use French medical terms to give an Ebola diagnosis without properly informing the patient or giving them a say.

"They spoke Swahili at admission, but when you come to the treatment, it is French, even English, which I don't understand."

Male resident, Tamende, Beni

French comprehension depends on a person's profession and education level. As the official language of DRC, French is taught from elementary school and used as the main language of instruction. Women, who often didn't finish school and perform more traditional roles as mothers and home-makers, usually have a lower level of French literacy. At the same time, women are the main caretakers when a family member is sick, and accompany them to the health center. Women described not seeking professional health care for fear of misunderstandings that could result in a false Ebola diagnosis.

"In medicine they have very many terms. If you have something like malaria, they don't call it *malaria*, they tell you it's *paludisme*. If you have never been to school, you won't understand a thing and you get confused. It's a reason why people no longer go for treatment. You're afraid that once you're there, they'll start using those words of theirs, and then they'll take you away without asking you."

Female resident, Mandrandele, Beni

Localized Swahili is the preferred language, but it is different from Congolese Swahili

Swahili is the lingua franca in eastern DRC and neighboring countries, but it is not uniform. Congolese Swahili varies from place to place, with the use of loanwords from other languages and grammatical adaptations. As TWB's <u>rapid language</u> <u>assessment</u> in Goma shows, Congolese Swahili speakers often do not understand seemingly basic words like *fomu* ("form") or *chanjo* ("vaccine") in standard Swahili. Instead, they use the French words *formulaire* and *vaccin*. There are also marked differences between Congolese Swahili and regional varieties of Swahili.

"On materials like posters and others they write in French, but for the message to reach its target it should be in the Swahili from here. Because there are some posters written in strange Swahili."

Male health worker, Boikene, Beni

In Congolese Swahili the word "headache" translates to *maumivu ya kichwa*, whereas in the Swahili spoken in Beni it is *kichwa kuluma*. The phrase "He has a headache" translates to *Ana maumivu ya kichwa* in Congolese Swahili, whereas a Swahili speaker in Beni would say *Ule kichwa yake iko na luma*.

"Health center" translates to *kituo kya afya* in high-register Congolese Swahili, which is quite similar to standard Swahili (*kituo cha afya*). But a Swahili speaker in Beni would say *ku dawa*.

The localized version of Swahili in Beni is influenced by Nande. This takes the form of different spellings, grammar, and loanwords. Pronunciation is also different. Standard pronunciation of Congolese Swahili can create confusion and misunderstanding for a speaker of localized Swahili in Beni.

English:	People are sick with Ebola
Standard Swahili:	Watu wana gonjwa Ebola
Congolese Swahili:	Batu bana gonjwa Ebola
Beni Swahili:	Bhatu bhana gonjwa Ebola
Beni Nande:	Abhandu bhalwere Ebola

Nearly all focus group participants preferred the local Beni Swahili over other varieties of Swahili to minimize misunderstanding.

"I feel comfortable when we speak Beni Swahili, which uses a few French words. It is not proper Swahili."

Male resident, Beni

Using a language that people understand increases trust

In Beni, the combination of a volatile security situation and a frightening disease has created a context of fear and distrust. Language affects whether a message and the messenger are trusted and believed. Most focus group participants told us that at the outset of the epidemic they had interpreted the use of languages they didn't understand as a threat. Consequently, they had thought Ebola was a weapon of war sent to kill them.

"Even if someone in my house was sick, with all their longwinded Lingala, I wouldn't know it. There would be three of them: one speaking Swahili, the second Lingala, the other French. And wasn't it all just a lot of words? One would speak Swahili, then the next would speak French, and the last one would speak Lingala and each one wrote down what they thought was important. That's what made us afraid: 'Can't they speak Swahili?' and then there were comments like 'They've come to kill us."

Female resident, Mandrandele, Beni

While communication has greatly improved, trust remains an important issue for people in Beni. Since the epidemic began, people feel they have been deprived of agency and freedom of choice. The fear of being taken to an Ebola treatment center or locked in isolation against their will is immense. The use of a language that people don't understand increases this fear, as people worry that misunderstandings might

How do you feel if a doctor or community health worker speaks to you in a language you don't fully understand?

"When you're ill, you're there with staff that speak only French. You don't understand each other, and then the trust is gone. He'll try to speak a Swahili that I don't understand. He may write things in his notes that I don't understand. So I wouldn't trust anything in his notes." Woman, Tamende, Beni

"I will think he is insulting me, because I don't understand what he says." Man, Kanzuli, Beni

"It makes the patient tell lies. [...] When he [the doctor] asks you, you might hide your illness, because you don't trust him, you don't really know how he can help you." Woman, Tamende, Beni

"I feel ashamed." Woman, Mandrandele, Beni

result in a false Ebola diagnosis.

Using a language that people understand is not only important in medical consultations. It is also critical in relaying health information. Most focus group participants said they had difficulty trusting someone they don't know and felt a general scepticism towards outsiders. In this context of distrust, the language spoken and the way of speaking become important markers of identity. Health information in localized Swahili or the Nande of Beni increases trust as it implies that the speaker is also from Beni. Ideally, health communicators would be neighbors from the same area. They would already be known to the community, or at least be accompanied by trusted local leaders. "I can trust you because I know you are from here. You can't stick a needle in me if I don't know you, I'll run away. In terms of communication, if I see that we don't speak the same Swahili, or your French is more complicated than mine, I won't pay attention to what you're saying. What needs to change is that they need to hire locals that people know to gain trust."

Male resident of Rwangoma, Beni

For the Beni residents we talked to, trust depends on the language you speak. This extends to other often subtle ways of speaking and communicating: body language and gestures, dress code, appearance, and manners. Keeping a cap on while speaking is considered extremely rude, while women in skinny jeans are embarrassing. In general, the way Ebola teams approach the population is considered overbearing and arrogant. "When the doctors arrive and we don't know them, their clothing isn't appropriate and respectful, with their big hats and *kanga dadi* (skinny jeans) and their Motorolas [...] we are afraid to approach them."

Female resident of Tamende, Beni

Whether they reflect cultural sensibility or a lack of respect, nonverbal communication affects people's confidence in Ebola teams and their messages. The fact that local health communicators, who are known to the population, are increasingly providing information on Ebola in Swahili is considered a great improvement. Choosing a language that people feel comfortable with is the first step to gain trust.

"If you enter a compound, you first ask politely which language people prefer to speak."

Female resident of Butsili, Beni

Key terms are still misunderstood and need to be translated and explained consistently

Specific medical terms used in the Ebola response are in French and are not consistently translated and explained. This creates confusion and frustration for community members. The meaning and context of key terms is often only vaguely understood. Allusions, interpretations, linguistic confusion, and non-translation further touch upon social sensitivities. Health communicators experience the same confusion around key terms, although to a lesser degree. They need more support to translate and explain key terms to prevent contradictions in the messages they relay.

Key terms in French create confusion, frustration, and fear

Ebola-specific terms and concepts were unknown to the population before the outbreak. In the absence of standardized translations, health communicators use French words to discuss Ebola, even when speaking a different language. For people who are not fluent in French or are less educated, seemingly simple terms like *cas probable* ("probable case"), *infectieux* ("infectious"), *guéri* ("cured"), and *épidémique* ("epidemic") remain unclear and hinder correct understanding. A key term like "virus" is still not universally understood; people in Beni tend to use the word "microbe" instead. Likewise, responders use variants of English terms like "swab" or "ring vaccination" in French. Neologisms like *swaber* and *vaccination en ring*, which translates to "vaccination in the (boxing) prize ring", create further confusion. Table 1 gives some examples of key terms and their interpretations by the population.

"There are many words in French that I don't understand. There are key words like 'virus'. When they talk about a virus I think of the SD card that can be damaged by a virus. Is this the same virus?"

Male resident of Kanzuli, Beni

Other French terms used in the Ebola response are known, but the literal meaning is not understood. In the worst case, this lack of understanding causes people to interpret such terms as a derogatory way of talking about the population. People know that a term like *cas suspect* ("suspected case") refers to a person who has symptoms similar to Ebola and whose diagnosis is not yet confirmed. Lacking knowledge of French, people understand the French word cas as the Nande diminutive *ka*. The French word *suspect* is interpreted in the criminal sense as a bandit, thief or troublemaker. Instead of "suspected case", people understand the literal meaning of *cas suspect* to be "little criminal". In the local understanding, response teams thus verbally reduce someone with symptoms similar to Ebola to a bad person with little worth.

"It is not good to change the language and to use words like 'suspected case', because in the community we know that if a person is a suspected case, they bring a lot of problems - either a bandit, a murderer, or a thief. When they call you that, it really hurts and you think, 'I've become a bad person, I'm going to die, there is no cure for me.' That's why it's important not to say it."

Female resident of Tamende, Beni

Some of the Ebola-specific terms are misunderstood due to the ambiguity and allusions evoked by a word. To be a "contact" is generally understood as one person having another person's phone number. To say that someone had contact with another person can also be understood as sexual intercourse. Accordingly, a "high-risk contact" is understood as sexual intercourse with a person with HIV, and a "contact of contacts" can also be understood as prostitute. Therefore asking if someone had contact, including physical contact, with a person who is confirmed to have Ebola is an ambiguous question.

"We didn't understand the language of the foreign doctors at first. For example, when they spoke of 'contact' without giving any more explanation, we wondered what he was talking about, what kind of contact ... telephone number? Sexual contact?"

Male nurse, Mabakanga, Beni

Other terms cause confusion due to their technical nature and lack of detailed medical explanation. Even if people understand medical concepts like "molecule" or "experimental vaccine", the meaning and implications of these words in the context of the Ebola response remain vague. The result is doubt and frustration, voiced especially in connection with vaccination and safe and dignified burials.

Table 1: Interpretations of key terms				
Surveillance				
<i>Cas</i> ("case")	In Nande <i>ka</i> is a diminutive.			
<i>Cas suspect</i> ("suspected case")	The word <i>suspect</i> is associated with criminals and violence. <i>Cas suspect</i> is understood as a criminal of little worth.			
<i>Cas contact</i> ("contact case")	A person with HIV			
Contact	Telephone number or sexual contact			
<i>Contact à haut risque</i> ("high risk contact")	Sexual intercourse with someone who has HIV			
<i>Contact des contacts</i> ("contact of contacts")	Prostitution			
Triage	Garbage			
Vaccination en ring ("ring vaccination")	Vaccination in the prize ring			
Vaccin expérimental ("experimental vaccine")	Associated with trials on animals			
<i>Suivi des contacts</i> (monitoring of people who had contact with a person ill with Ebola)	Distribution of free food			
Psychosocial support				
<i>Vainqueur</i> ("winner")	Someone who has won in the "vaccination in the prize ring"			
<i>Riposte</i> ("response")	War, attack, battle			

Medical care				
Ambulance	Synonymous with death; no return home			
EPI ("personal protection equipment")	People wearing personal protective equipment are referred to as <i>kinyawu</i> ("monster").			
<i>Déchargé non-cas</i> ("released as no- case")	Escape from death			
<i>Isolement</i> ("isolation")	Waiting for death			
Infection Prevention and Control				
Eau chlorée ("chlorinated water")	Water that contains the Ebola virus, water that is not clean			
Décontamination ("decontamination")	Washing hands			
Virus	Associated with computer technology			
Molécule	Cassava			
Safe and dignified burials				
EDS ("safe and dignified burial")	Death after mutilation			
Swab	(Unknown, not understood)			
<i>Décès communautaire</i> (refers to the death of an Ebola patient outside of an Ebola Treatment Center)	Death of the community			

"We were told that the vaccine is still in the experimental phase, and I will never forget that word in my life. When I checked in the dictionary, I realized that I had become a guinea pig, and I immediately had doubts. This word was not good for me... I had become part of a test, and a test can fail." Male community outreach worker, Tamende, Beni

The lack of contextual explanation and understanding also impacts less complex terms. Words related to the epidemic like *cas suspect, isolement* (isolation) or "ambulance", and the abbreviations "TC" and "ETC" for transit center and Ebola treatment center, are equated with death. These words are so strongly stigmatized and feared that most people avoid using them. Even health workers refrain from pronouncing them because they know that many patients run away when they hear these words.

"ETC is a word that scared us. We're really afraid of this word."

Pharmacist in Kanzuli, Beni

Words relating to some symptoms of Ebola and to reproductive organs, sex, and bodily fluids cause embarrassment when used in public. Talking about diarrhea or the sexual transmission of Ebola, especially in a situation where others can overhear, is considered disrespectful. All Ebola communicators should know how to address these sensitive topics in a respectful way. This entails knowing and using local euphemisms where appropriate.

"There are terms we do not say in public, outside, where anyone can hear. You see, these health workers who came here for Ebola don't have any taboos in their culture. They'll say anything in public and it stigmatizes the patient." Female resident of Tamende, Beni



To soften a harsh language, key terms are not translated but replaced by description

Communication about Ebola takes place in a context of sociolinguistic sensitivities, frustration, and fear. Local people consider many of the terms used in the Ebola response harsh, and react negatively to them. Health communicators soften this harsh language by explaining and replacing key terms with descriptions. Table 2 shows some gentler descriptions health communicators use to explain key terms.

"The words that are used in the context of the epidemic are so blunt that they can be frustrating to the patient. So if the health worker can explain, instead of using [a term like] 'suspected case', and even explain in Swahili, that would facilitate things."

Male health worker, Mabakanga, Beni

Explanations are a more socially acceptable solution for words that people perceive as stigmatizing and frightening. These include "suspected case", "isolation," or "TC." Explanations not only soften the language, but also try to uncouple the terms from the Ebola context to make them less intimidating.

"I say that isolation is a room to rest where we have to be alone, because we can't know another person's state of health. They might have a cough or a cold and they could infect you if you're in the same room."

Health worker, Butsili, Beni



Table 2: We asked health workers how they would translate these key terms when talking to community members.				
	Nande	English meaning		
<i>Centre de traitement d'Ebola</i> (Ebola treatment center)	Ekiharo oho vangana ku twanira	A place where you can be taken care of		
	Ekiharo ekirimo mivatsi	The place where there is healing		
	Kilamiro che Ebola	Health center for Ebola		
	Swahili	English meaning		
<i>Centre de traitement d'Ebola</i> (Ebola treatment center)	Kituo ambakyo kina pachwa tusaidiya kukunga ama kutunza mangonzwa ya virus ya ebola	A center where we are helped to protect ourselves and even cure Ebola		
	Kituo ya matunzo ya Ebola	Care center for Ebola		
	Swahili	English meaning		
<i>Suivi de contact</i> (contact tracing)	Ku fatililiya mutu yoyote ambaye alikuwa kando ya mungonzwa	Monitoring of all people who have been close to a sick person		
	Swahili	English meaning		
<i>Cas suspect</i> (suspected case)	Inataka fanana ile magonjwa, wende pimisha.	It resembles the disease, and you need to get treatment.		
	Nande	English meaning		
<i>Cas suspect</i> (suspected case)	Wamasa na makoni hawasosire ovukoni oh vwavirivya vuka tu tesa.	You are coming with a disease that resembles the disease that makes us suffer.		

Health communicators struggle to understand and translate Ebola-specific terms

It's also difficult for health communicators, including community health workers, to understand key terms. Health communicators identified some of the many abbreviations used in the response as being among the hardest parts of their training to understand. Examples include EDS (safe and dignified burials), CTE (Ebola treatment center) and PCI (infection prevention and control).

Nearly all health workers we talked to had completed several training sessions in French and Swahili. They usually did not receive reference materials to take home. Training in French further limited understanding for those who were not fluent.

"Many training sessions were in French, although many didn't have good enough French to understand. They just looked at the pictures and had a laugh until it was over."

Health worker, Boikene, Beni

Health communicators don't receive guidance on adapting messages so that they convey important information in a way that people find acceptable. Without standardized translations, health communicators need to find the right words to translate key terms unsupported. Explanations and translations depend on the knowledge and communication skills of each individual. The information relayed is thus not consistent and may be contradictory.

"Today you'll see around four teams on the ground and all say they include community outreach workers. [...] And each one has their own way of speaking. Let the community sensitizers teach the same content. That way there's just one message, not several."

Female resident of Tamende, Beni

Health communicators need more support to give clear explanations

Health communicators cannot relay information correctly if they don't fully understand the information themselves. To effectively engage with communities, health communicators need regular training to refresh their memories and provide updated information. Participants in the focus groups highlighted the need for training in nearly all aspects of the Ebola response. That includes training on the origin, symptoms, and prevention of Ebola. They also requested updates on vaccination, referral procedures for suspected cases, and treatment. With the growing number of Ebola survivors, health communicators also require training for follow-up health care and psychosocial support to survivors. They also requested training on communication strategies. To prepare them to relay information in the languages local people understand, training should be in Swahili and Nande as well as in French.

Due to the dynamics of the epidemic and the changes in the response, health communicators often don't have detailed knowledge of the latest developments. They lack communication tools that help them to provide accurate and up-to-date information. This leaves them unable to answer people's questions. Any answers they do give might contradict what other communication teams or the media have said. This is frustrating to communicators and communities alike. In the worst case, it breeds contempt for the communicators, who are seen as incompetent and just making money out of Ebola.

"I'm ashamed, because I can't answer their questions, and all the frustration of the population is turned against us communicators."

Female health communicator, Boikene, Beni



Ebola communicators do not always have a background in health. They sometimes lack the experience to address a sensitive topic like Ebola, especially if it concerns a person directly. Their communication style is sometimes perceived as brusque and inappropriate, and can prompt withdrawal or even menace by their questioners. Although trust in the Ebola teams is returning in Beni, health communicators face rumors and fears that demand a high degree of empathy, linguistic sensitivity, and persuasive skill. Building trust remains a central concern for community outreach workers, who need to be able to talk about possible symptoms of the disease to do contact tracing. Without the necessary support and training, health communicators are left to manage these challenging situations alone.

"You have to recruit community outreach workers in the health sector, because we have ways of approaching people who are ill. After all, people have lost their lives for not knowing how to talk. Before you send them out, you have to train them well: how to approach people, not to say directly 'You have a temperature,' how to persuade people."

Health worker, Mabolio, Beni



Clear information can restore doctor-patient relationships

Health workers face a decline in the reputation of their profession. People call for local doctors and health workers to be more involved in the response, and in treatment especially. Yet poor understanding of the disease has also strained relations between patients and local health personnel. As early symptoms of Ebola resemble those of other better known and less dangerous diseases, people initially felt their doctors were lying to them. This has damaged people's confidence in the competence and trustworthiness of local doctors and health workers.

"Medicine is no longer respected because of [health workers'] bad behavior. Before when you saw a health worker, it was like a second god, because if you got sick, you knew it was the health worker and God who would heal you. But now if you get sick, you think to yourself: 'God, give me a miracle here in my home. I won't go for treatment because if I do, God will test me and I could die."

Female resident of Mabakanga, Beni

New medical procedures, like triage on admission, social distancing, and keeping suspected cases in isolation, further impairs doctor-patient relationships. The wearing of personal protective equipment has even earned doctors and health workers the title *kinyawu* ("monster"). Due to the medical procedures specific to the epidemic, people fear that they no longer have the right to informed consent. They feel they are under general suspicion and poorly received. They distrust the technical equipment used to take their temperature. They told us that some people actively try to lower their temperature before going to the health center. Instead of being able to talk about their health problems, they feel they have to prove their good health to the doctor.



"They say faith is a cure. [...] You come to the doctor knowing you can't be cured. Then there's the stress of being denigrated at the entrance, and then you wait a long time while the others pass through quickly. And when you finally get in, you have no confidence in what happens next. Even the drugs can't cure you."

Male resident of Tamende, Beni

Health workers are aware of the difficult relationship with patients. They explain popular distrust as the result of a lack of knowledge and understanding of the disease, combined with a traumatic history of violence. Health workers feel like people do not value them but view them as enemies. Intimidations and threats against health workers (and health communicators) have decreased, but they still happen. Community health workers report feeling humiliated and denigrated. The hostility they face in turn causes health workers to feel contempt for their patients.

"We have become enemies of the population, each member of the nursing staff is considered as someone who sacrifices the population. This is because of the trauma that is already ingrained in the heads of our people. They are really traumatized. They think we are not really people, they are intimidating us. You feel belittled and humiliated in front of the patients, that's why we start to scorn them when we see them, we call them names"

Anesthetist, Kanzuli, Beni



People have legitimate questions and need detailed and up-to-date answers in plain language

People are learning. After more than a year of living with Ebola in Beni, knowledge of the disease has greatly improved. Likewise the Ebola response is adapting to new knowledge and the dynamics of the epidemic. Communication strategies change, new procedures like transit centers are established, eligibility for vaccination is extended, and survival rates improve. For the population these changes raise legitimate questions and sometimes doubts. Is it really safe for pregnant women to be vaccinated now, although a few months ago they were not eligible for vaccination? What is the difference between a transit center (TC) and an Ebola treatment center (ETC)? How can a person be cured but still carry the virus in his semen, and how contagious is it? People want answers to these and many other questions. They need detailed and up-to-date information in plain language.

"We need explanations on the molecule. They need to make me understand what molecule means. That would really help, even though I'm not from the health sector. They need to explain this the same way they have explained how to wash your hands. And if there is a formula for the molecule, we need to understand this."

Male resident of Tamende, Beni

29

Dynamics in the response need to be explained to counter doubt and disbelief

People generally understand the basic information. However new information and details seem to contradict what had been said before. One of the most obvious examples concerns eligibility for vaccination. Initially, pregnant women and people with chronic illnesses could not receive vaccination, but now they can. People want to know why vaccination no longer poses a risk to those individuals. Their concern is understandable.

Without comprehensible, detailed explanations of new developments, people wonder if they are being told the truth. They begin to question other information, and rumors start. Transparent and accessible explanations will help people to identify and verify reliable information.

"I understand the information about Ebola, but with difficulty because there are no truths. People in the response contradict each other about the disease."

Male resident of Kanzuli, Beni

Young people in particular doubt much of the information they receive:

"Age can make a difference: young people understand better than old people. But old people, once convinced, accept the disease, while young people tend to be very analytical about it."

Health worker, Mabakanga, Beni



People want explanations of "why", not just "what"

People want precise, detailed and up-to-date information that reflects the dynamics of the outbreak and the changes within the response. The most sought-after information concerns medical knowledge and the characteristics of Ebola, vaccination, treatment, and burials. Interviewees ask for detailed, complex explanations that go beyond "If you go early to the ETC you can be cured," or "Ebola is transmitted by fruit bats." They have questions about the exact differences between the four drugs tested in the beginning of the response and how the two chosen drugs work. They want to understand how fruit bats became the carriers of a new disease in the first place. One of the main issues that still creates confusion and doubt is the similarity between Ebola symptoms and those of other diseases. People cite the symptoms of Ebola by heart, but they don't understand how such apparently harmless and common health problems can also be symptoms of a deadly disease.

"We had fevers and colds before, but now if you have one of these signs you need to hide. We always have colds in Beni, but today having a cold is a sign of Ebola. We don't understand that. We have always had headaches"

Male resident of Kanzuli, Beni

Study participants voiced frustration at the lack of answers.

"When you go to get vaccinated they answer your questions, but afterwards they never have time."

Female resident of Mandrandele, Beni

People need hopeful messages

Communities yearn for positive, hopeful messages. After more than a year of the Ebola outbreak, people say they are exhausted. They do not want to hear messages that further increase fear. Instead, they are looking for signs that the disease can be overcome.

In their hope of being rid of Ebola, people have changed how they speak about it, often talking about the disease in the past tense. Cases in Beni have steadily decreased since the peak of the epidemic between March and July 2019. People feel they are moving towards the next phase, if not the end of the epidemic. However, many who interpret the epidemic as a business wonder if eliminating Ebola is really the goal. People therefore stress the improvements that have already been achieved.

"People think it's coming to an end. We already socialize more. At least we can breathe: it's not killing at the same rate as before. Dr Muyembe said [Ebola] will be finished in four months. An end to the disease - that promise is still in people's hearts."

Focus group facilitator in Beni

It is important to acknowledge the downward trend of the disease in Beni to avoid losing touch with the population. Messages should be adapted to combine health warnings with a more hopeful perspective on the future. These might include: "To ultimately overcome Ebola, we need to continue to observe hygiene rules" and "To make ending the epidemic a reality..."



Complex information needs plain language

People want information in what they call *langage communautaire* ("community language"). That means, in a language and style they understand, using words and concepts they are familiar with. Likewise, communicators need communication materials containing comprehensible explanations so that they can pass this information on to communities.

Plain-language writing provides an established, evidence-based framework for clear communication in the response. It highlights the importance of predicting and providing the information the audience needs, structuring it logically, and using words that are familiar to the audience. By reducing reader effort, plain language communications help all readers, regardless of their education level. Preparing future communications in plain language will therefore benefit patients, communities, health communicators, and doctors.

The health sector has extensive experience applying plain language principles, so considerable guidance is available. The Centers for Disease Control and Prevention have consolidated various plain language resources in the Health Literacy section of their website.



Communication formats must adapt to people's preferences and allow them to engage

How information is relayed helps determine how far it answers people's questions and whether they believe and remember it. People are looking for precise and detailed information, so they prefer formats that allow them to ask questions. They also rely on personal contact with communicators to assess the credibility of the information they receive. Involving trusted leaders and community members in communication events further increases trust. Printed information that offers detailed explanations is likewise required.

Women prefer face-to-face communication with health communicators they know

Focus group participants told us that they prefer to receive information in person, either in community meetings or in door-to-door sensitization activities and educational talks in small groups. For them these channels offer the possibility to ask questions that they might not dare to ask in a larger group. The downside they see in door-to-door sensitization is the risk of not talking to an expert. On the other hand, community meetings can involve local religious and political leaders, community outreach workers, and local health workers, who increase trust in the information given. If trusted leaders are present, bringing in foreign experts to explain more technical details is also more acceptable. The community outreach worker would then be able to translate their explanations in a language and style that people understand.

"Talking to people is very important. You can bring billboards, you can write on them, but if people don't understand, they will not know how to ask questions. The important thing is to talk to people face to face, explain to them what they see on the poster. It's about talking with people and interacting with them."

Doctor, Mandrandele, Beni

Women in particular prefer to receive information in person. They have less access than men to other information channels and receive most of their information by word-of-mouth. According to the health communicators we talked to, women are also more likely to believe rumors about the response and the non-existence of Ebola. Women often find it easier to trust information they receive from people they know personally and who are from the same neighborhood. Familiarity and personal contact are more important than the gender of the health communicator.

Other audio formats like radio and megaphone announcements are likewise popular, but have a gendered audience. While the daily radio bulletin "Koma Ebola" is well known, it is mostly men who own and listen to the radio. Women prefer megaphone announcements delivered in the neighborhood in the early morning. The gendered access to radio is reversed with smartphone use. Younger women especially told us that they listen to the radio on their phones. But given the many rumors and unanswered questions concerning Ebola, in-person communication remains the most trusted channel of information.

"Messages on the radio are a little difficult, because you don't know who is on the radio: they could be being used. For example, sometimes you hear that someone has been cured at the ETC. People say these are soldiers' wives who are paid to give testimony as Ebola survivors. But when it's word-of-mouth, you see the person. On the radio you only hear without seeing."

Male resident of Kanzuli, Beni



Documentary films inform about the reality on the ground but are rarely shown

Audiovisual communication, especially documentaries, gets a lot of attention. We showed a documentary video on the Ebola treatment center in Mangina to young focus group participants. They noted the smallest details and engaged in an animated discussion of individual scenes and statements. Participants weighed the slightest contradictions against the credibility of the video. They considered the documentary to be evidence against the rumor of the disease being a scenario staged by the "Ebola people" to enrich themselves. This gives valuable insight into the rumors and conspiracy theories that affect communication. With the existing demand for detailed and accurate information, the only regret that our participants voiced was that this was a documentary from Mangina, whereas they would have liked a localized video showing the reality in Beni.

Documentary videos are limited and rarely accessible. The audiovisual archive of the response contains a number of documentary videos, but they are also apparently not used or regularly updated and expanded. Most Beni residents do not own a TV and have limited access to electricity; they have few opportunities to watch films. Ebola communication teams lack technical equipment to project documentaries regularly when visiting communities. Video forums and mobile cinema can be effective ways to communicate about Ebola and counteract rumors. There should be an opportunity to ask questions and discuss impressions after each screening. This is likely to be particularly effective among young people, who voice the most doubt about Ebola.

Health communicators consider audiovisual material a helpful alternative to posters. They feel that posters don't convey enough information and wither away quickly. Participants in our focus groups would like educational videos on correct handwashing and broader prevention measures. In particular they would like videos on vaccination, the process of referral to a transit center, insights into Ebola treatment centers, and procedures for a secure and dignified burial.

"I would like us to distribute hand washing facilities to all households as well. And for the health structures we need a small screen at the reception for films that show how to wash your hands, and how to protect yourself against the disease."

Community health worker, Boikene, Beni

Pictorial communication needs to be accurate as people read images literally

We discussed pictorial materials used in the Ebola response and in other health campaigns with focus group participants. We used the "old" Ebola posters as well as the newly designed posters, banners, and leaflets that contain images and explanations in French and Swahili. All participants, regardless of their age or gender, considered pictorial materials highly important. They were particularly interested in the more detailed leaflets and requested that these should also be available in Nande and Lingala. However women told us that they had greater difficulty understanding these kind of materials because they can't read the text or they are confused about the images. Most posters we saw in health facilities and occasionally on the road include supplementary text explanations in French. Women in particular are less likely to be able to read French, so they can only access the pictorial part of the message.

"We see the posters, but often the health workers do not explain them to us, unless you ask: what does this image mean?"

Female resident of Mandrandele, Beni

Most images are not self-explanatory and need explanation. They lack important details, or depict details that convey a different message than the intended one. People also get confused about the order in which to read images and prefer these to be numbered. Health communicators need to explain posters picture by picture so that people understand the message correctly. In that way posters supplement face-to-face communication, substituting for the lack of more extensive information materials like leaflets, manuals, or flash cards.

"If the health worker showed us pictures, we would have more knowledge about the details of diseases. With a poster you can understand the message. Like with Ebola, we know that you should not touch the body of someone who has died, not go near someone who is sick, or eat the meat of a dead animal. There should be more detail on hand washing."

Male resident of Tamende, Beni

People read pictures literally. Small details can be confusing or disturbing. To convey the correct information, pictures need to be precise. An image showing a woman in a short skirt as part of the safe and dignified burial team raises concerns. Not only is her dress culturally inappropriate, but it is not culturally acceptable for a woman to perform a burial. To clarify that the woman represents the psychosocial support team requires an additional picture showing the woman sitting and talking with family members of the deceased.

"On the poster there is a picture people often ask me about: why did they draw a man having a pee? And his face is very badly drawn. People say it really makes a mockery of us. That picture needs to be changed."

Male community outreach worker, Mabolio, Beni Colors also convey a message and communication materials should be tested to understand how people interpret the use of different colors. On the "old" Ebola posters red and gold/ yellow were the main colors. The choice of colors reinforced the perception that Ebola was a business: red symbolized death, whereas gold/yellow represented wealth.

"When I see this picture, I see death. The red color symbolizes death, the yellow color symbolizes wealth. And our interpretation is that our death enriches others. You could use blue, which means peace, instead of red."

Male resident of Kanzuli, Beni



There are not enough printed materials and they lack detail

Posters and banners on Ebola are a surprisingly rare sight in Beni. Some of the larger placards in town were torn down in frustration on the anniversary of the Ebola outbreak. Smaller posters in the neighborhoods "disappear" a few days after they are put up. Focus group participants told us that this is not necessarily an act of vandalism. Instead, they suggested it is an expression of the lack of available information. Often young people remove posters in the streets and take them home to have permanent access to the information.

Most posters in Beni are inside the health facilities. Exposed to the weather, many of the posters we saw were run down and sometimes difficult to read. In other places, posters were hung in the reception office to protect them from the rain, but were not visible to patients who are not allowed to enter the office.

"We need well-laminated posters, so that even if it rains, they won't deteriorate."

Male health worker, Boikene, Beni

We also discussed the new Ministry of Health/UNICEF leaflets in focus groups. Participants greatly approved of them and wanted to keep them. The leaflets cover vaccination, safe and dignified burials, Ebola treatment centers, and mobility. Each topic is addressed in a separate leaflet and in more detail than the old version, which covered all aspects of Ebola. As much as the new materials are welcome, focus group participants still pointed to the lack of other information. The fact that the information was provided in four separate leaflets was also considered less than ideal.

Focus group participants had very precise ideas about the kind of printed material they would prefer. Printed information should be provided in one extensive brochure covering all aspects of Ebola, and available for people to keep at home. It should include:

- all available information presented chronologically
- · detailed medical and easy-to-understand explanations
- Swahili, French, Nande, and Lingala translations
- well illustrated, numbered images, showing consecutive steps
- information on how the response works.

What this means for your program

Many organizations are involved in communicating with community members about Ebola. They can help to improve understanding by providing better support to health communicators on language, content, and communication methods:

Provide information in local languages

Using a language that people feel comfortable in increases understanding and trust. French and Swahili alone are not sufficient. Information must be available in local languages.

Use localized Swahili

National languages like Swahili vary from place to place, adopting grammar, spelling, loanwords, and pronunciation from local languages. For communication in Swahili, use localized Swahili to ensure comprehension.

Provide regular refresher training to health communicators

Communicators struggle to understand all aspects of the Ebola response. Provide regular training to health communicators, in their languages, on aspects that remain unclear.



Support health communicators to answer questions

Communicators have difficulty translating key terms and providing clear information in simple, accessible language. Provide them with tools and training to facilitate accurate and up-to-date information relay. These should draw on health communicators' understanding of more culturally acceptable wording, while avoiding inaccuracy and negative connotations.

Communicate about "why", and not only about "what"

People have largely understood the basic information on Ebola. They need detailed and up-to-date information on vaccination and treatment. And they want to understand developments in the response. Regularly update messages and explanations to meet evolving information needs.

Use hopeful messages People need positive messages that decrease fear and point to an end of the epidemic. Include people who have recovered from Ebola in communication efforts. Adapt existing messages by including phrases like "To ultimately overcome Ebola..." or "To make ending the epidemic a reality...".

Hyper-localize communication

People place more trust in information they receive from someone they know. This study suggests that communication can be further localized by involving local leaders and communicators from the same neighborhood.

Give preference to face-to-face communication

People have legitimate questions and need information in formats that enable them to engage. Community meetings, educational talks, and door-to-door sensitization best meet their communication needs.

Develop and test comprehensive leaflets, posters, and pictorial materials

Existing printed materials are not selfexplanatory, lack detail, and convey confusing messages. Tailor all materials to expressed preferences and practical needs and test for comprehension and acceptability.

Use audiovisual material

Documentary films are available and offer insights that communities want. Provide communicators with the equipment to make audiovisual material accessible to community members.



TWB can help

TWB aims to help break the Ebola transmission chain by improving two-way communication with the affected population in their preferred languages and formats. This entails understanding current language challenges and building multilingual communication capacity to address them.

TWB's support is designed as a common service across the response, in the interests of consistency, efficiency, and effectiveness. It also builds on similar language advisory support and capacity building provided in Bangladesh, Mozambique, and Nigeria.

TWB's current and planned support to the Ebola response includes the following activities:

Language and communication assessments and formative research

This includes studying comprehension levels and language- and formatrelated communication barriers among communities in the affected provinces. TWB also maps the languages spoken and understood by affected people by location, and supports response partners to collect the data to be mapped. TWB relays new learning on language issues to responders in order to inform all risk communication and community engagement.

Development of training, guidance, and tools

TWB draws on the findings of language and communication assessments to build multilingual communication capacity across the Ebola response. This includes developing practical guidance on reducing misunderstanding and miscommunication, terminology tools and targeted workshops for frontline workers, and training in multilingual communication. We aim to train a high proportion of women, to facilitate improved communication with female community members.

Building a community of translators for local languages

For languages with relatively small numbers of speakers and/or without mother tongue education, professional translators are often not available. TWB identifies and trains speakers of the relevant local languages to provide translation services. This has the added benefit of building translation capacity in local languages for future needs. TWB also builds on its existing network of translators in Congolese Swahili and French. This includes working with language experts in DRC and elsewhere to ensure professional quality standards are met.

Language support for responders on the ground

This involves field-testing written and audio documents and messages in French, Congolese Swahili, and local languages. TWB translates and tests relevant terminology in local languages, to create a multilingual glossary and related tools. TWB also localizes messages and information to align them with the communication needs and preferences of the affected population. We will build capacity to offer wider translation support in local languages over time as well as plain-language assessment and advice.

Supporting efforts to enable data collection and accountability in local languages

TWB provides advice, training and translation support for effective multilingual data collection and analysis. TWB also supports efforts on language-sensitive community feedback mechanisms.

Acknowledgements

TWB can also provide language technology solutions to support interactive information provision. These include developing machine translation for local languages and automatic voice recognition to improve information access for less literate individuals.

Translators without Borders would like to sincerely thank all the individuals and organizations that supported and contributed to this study. In particular we are extremely grateful to the International Rescue Committee's team members in the Democratic Republic of Congo and elsewhere for their daily contribution to making this study a success.

Christine Fricke, lead researcher, authored this report and conducted the field study with a team of researchers from Beni: Vinciane Sibkasibka, Diane Ngowire, Eusebie Ngwalangwala, Eric Kapitula, Chirac Paluku, and Nehemie Babikana.

Translators without Borders believes that everyone has the right to give and receive information in a language and format they understand. We work with nonprofit partners and a global community of language professionals to build local language translation capacity, and raise awareness of language barriers. Originally founded in 1993 in France (as Traducteurs sans Frontières), TWB translates millions of words of lifesaving and life-changing information every year. In 2013, TWB created the first crisis relief translation service, Words of Relief, which has responded to crises every year since.

For more information about this study or to find out how Translators without Borders is supporting the Ebola response in DRC, visit our website or contact: <u>drc@translatorswithoutborders.org</u>.

This study was supported by grant funding from Gilead Sciences, Inc. via the International Rescue Committee and by the H2H Fund, which is supported by UK aid from the UK government' . Gilead Sciences, the International Rescue Committee, the H2H Fund and the UK government have had no input into the development or content of these materials.







Department for International Development

