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The Language Factor

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Lessons for the 11th Ebola outbreak on adapting to the language needs of communities learned during the 10th Ebola epidemic in the Democratic Republic of Congo



Previous Ebola virus disease (EVD) outbreaks offer lessons for public health experts responding to the 11th outbreak. This review highlights that responders need to build more trust with the communities they serve. It suggests that language is fundamental to that.

The ninth, 10th and 11th outbreaks of Ebola virus disease have taken place in very rapid succession. Responders to the 11th outbreak need to incorporate lessons learned from previous outbreaks. Translators without Borders (TWB) research and experience supporting risk communicators in outbreak response show they should pay special attention to building trust with communities. The public health experts engaged in the 11th response will be able to draw on progress in treatment and vaccine development, but these advances will only be effective if communities accept them. This report alerts responders to **the importance of language in building trust and effective communication** with people facing Ebola and other epidemics.

The report is organised in three sections:

Section 1

Focus on the 10th Ebola outbreak: An outline of the evolution of the 10th Ebola outbreak across health zones and language communities.

Section 2

Local languages and localized communication: TWB's findings on language and communication during the 10th Ebola epidemic in eastern DRC.

Section 3

Lessons and tools for the 11th Ebola outbreak and future epidemics in DRC

What you absolutely need to know:

- People at risk of contracting Ebola need information to keep themselves and their families safe. Information they don't understand will not help them. They need clear communication in plain, localized language, in a format they understand, and through channels they trust.
- In the 10th Ebola outbreak in DRC, the use of French and Swahili, which many local populations did not understand, **exacerbated mistrust** between health workers and communities, hampering vaccine sensitization efforts.
- In general, language barriers pose the greatest challenges to women, older people, and other vulnerable groups when it comes to obtaining the information they need.
- Because language use and information preferences vary by location, further research is needed to determine the most effective approaches to risk communications and community engagement in the 11th Ebola outbreak.

Section 1 Focus on the 10th Ebola outbreak

Three outbreaks in quick succession

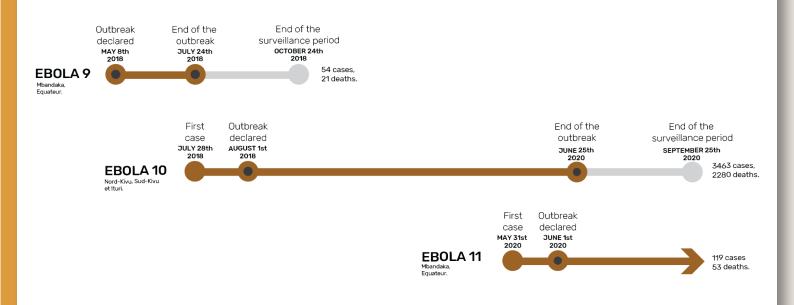


Figure 1: Timeline of Ebola outbreaks in DRC. The 9th Ebola outbreak in Equateur, the 10th Ebola outbreak in North Kivu, South Kivu and Ituri, and the 11th outbreak occurred in DRC in rapid succession.

Ebola Virus Disease is a highly infectious and lethal hemorrhagic fever that was first identified in 1976. The 10th Ebola outbreak in eastern DRC counted 3,470 cases and 2,287 deaths and was the deadliest in the country. The 10th outbreak was also the second-largest outbreak of the disease anywhere, after the outbreak in West Africa that began in Guinea in late 2013 and ended in early 2016. The 10th outbreak was declared on August 1, 2018, in Mangina, North Kivu Province, but global health authorities believe it had been growing undetected in the province while responders were busy with the ninth Ebola outbreak in Equateur.

Notification of the first cases in the 10th outbreak (25 cases on July 28, 2018) came within days of the end of the ninth outbreak as shown in Figure 1. Similarly, health authorities had not yet declared the end of the 10th outbreak when the 11th outbreak was detected on May 31, 2020 in Equateur. Thanks to genetic sequencing, DRC's National Institute of Biomedical Research has established that the three outbreaks are distinct. It is the first time three Ebola outbreaks have nearly or actually coincided.



The 10th Ebola outbreak in context

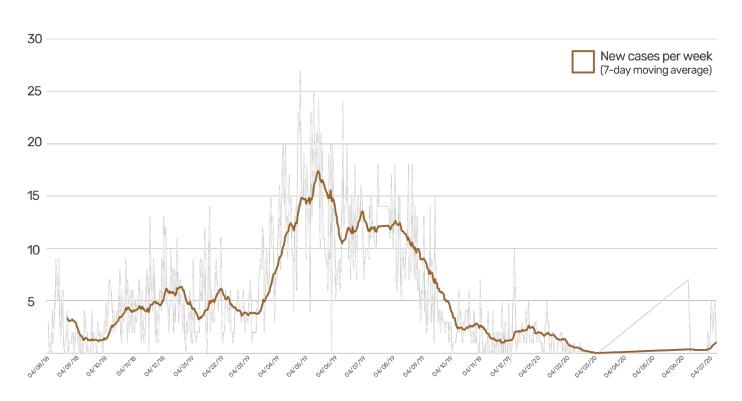


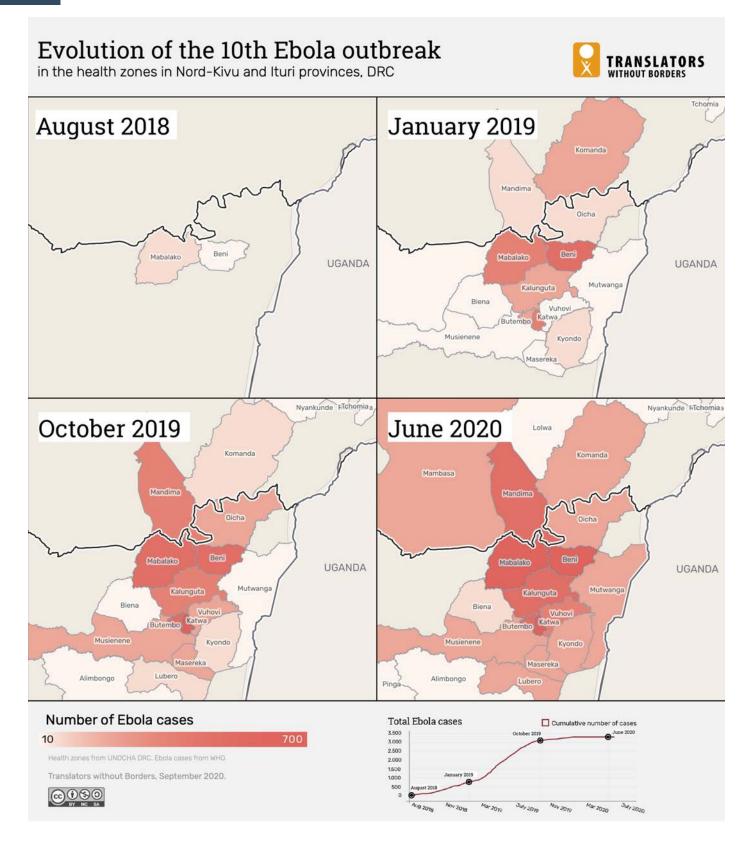
Figure 2: Weekly caseload from August 2018 to June 2020 (WHO and DRC Ministry of Health). The number of cases peaked in mid-2019.

The first cases of the 10th Ebola outbreak were in remote Mabalako, but the disease soon spread to a large city, Beni, and then to the neighboring province of Ituri. This was the first time Ebola had emerged in an area of DRC with high population density and mobility, and with active regional and international trade links - factors that could help the virus spread more quickly. The area, characterized by armed conflict and host to a UN-mandated peacekeeping force, also presented security challenges and complex political dynamics. Surveillance and contact tracing proved difficult for health workers.

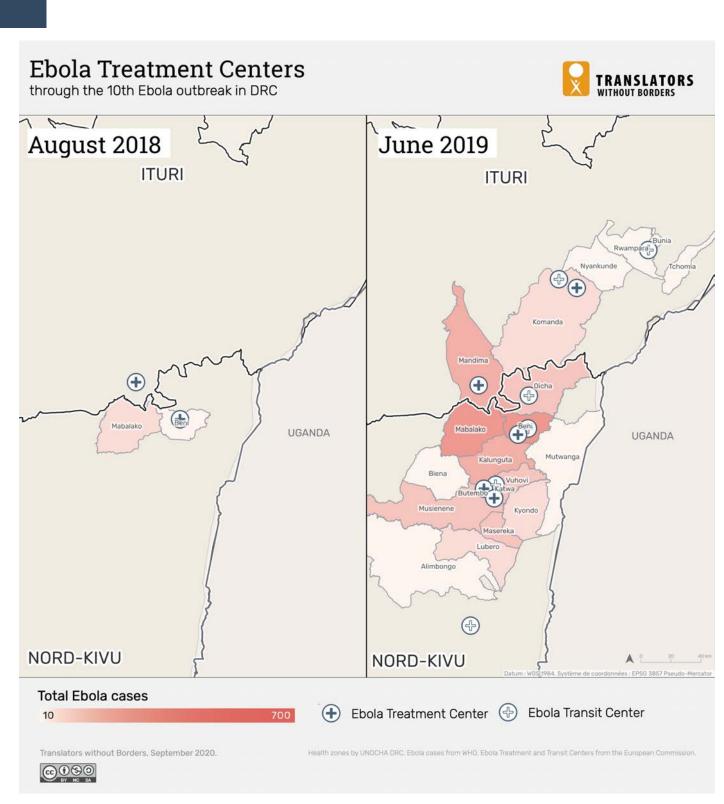
In June 2019 the outbreak spread to Goma, a city of roughly 2 million people and the provincial capital of North Kivu. Goma, on the border with Rwanda, is also a major aid hub. Many feared the virus would spread to Rwanda or Uganda, particularly when people infected with Ebola traveled to Uganda in June and August 2019.

Although only four people were infected in Goma, on July 17, 2019, the World Health Organization (WHO) declared a Public Health Emergency of International Concern.





Map 1: Evolution of cases across health zones during the outbreak in eastern DRC. The outbreak spread across a large number of health zones, touching different language communities.



Map 2: TWB's mapping of Ebola Treatment Centers and Transit Centers in heavily affected health areas, at the start and peak of the epidemic (2018 and 2019), shows the rapid geographical spread of the response.

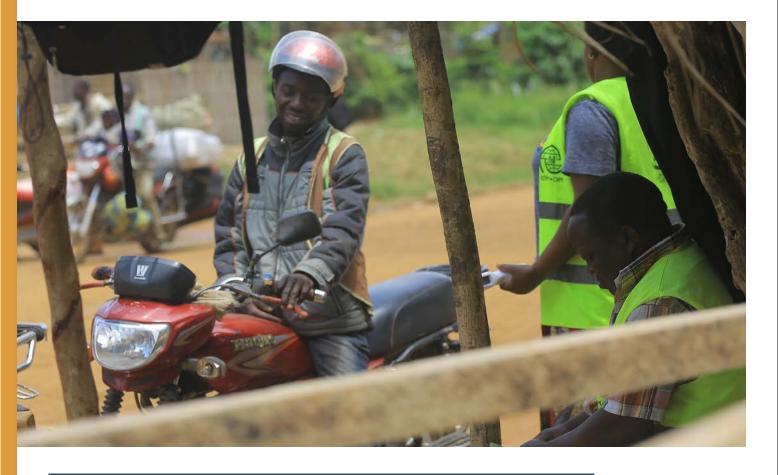
Thanks to groundbreaking medical advances, by the time public health authorities declared the 10th outbreak over on June 25, 2020, more than 300,000 people had been vaccinated and over 1,100 people had achieved Ebola survivor status after undergoing treatment.

A response hindered by distrust

The response to the 10th outbreak of Ebola in DRC was marked by affected populations' high levels of distrust in health workers. Some in the community alleged that the aid effort was a money-making venture. These responders faced unprecedented levels of violence: WHO recorded more than 300 attacks on Ebola health workers in 2019, several of them fatal.

In a Harvard Medical School-led study <u>published in the Lancet</u>¹ based on a September 2018 survey of 941 people in Nord Kivu, just 349 (36%) said they trusted local authorities. And while 91% said they had received information on how to protect themselves from Ebola, 25.5% also said they believed Ebola did not exist, 32.6% said they thought Ebola was fabricated for financial gains, and 36.4% said they thought Ebola was fabricated to destabilize the region. Over 92% said they had heard at least one of those rumors, and nearly 46% said they believed at least one of them. The study found that the less people trusted institutions and the more they placed their trust in rumors, the less likely they were to adopt preventive behaviors or accept a vaccine.

Responders' failure to gain acceptance from target groups, a problem referred to as "community resistance" or "community reticence," severely impeded their access in the affected area. The escalation of ongoing conflict in North Kivu and Ituri in late 2019 further complicated core response activities including health care provision, contact tracing, surveillance and vaccination, and, of course, risk communication and community engagement.



¹Vinck P, Pham PN, 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 May;19(5):529-536. doi: 10.1016/S1473-3099(19)30063-5. Epub 2019 Mar 27. PMID: 30928435.

Section 2 Local languages and localized communication

The 10th Ebola response's difficulties in engaging with communities exacerbated the trust issues responders faced.

Evidence of the importance of localizing risk communication has been mounting as academics and practitioners take stock of lessons learned from recent public health crises. In a 2018 review of findings by nongovernmental organizations and others published in the journal Health Communications,² the WHO noted that one of the most important considerations for risk communication is "tailoring" content to specific local populations, gender, circumstances and language.

But at the outset of the 10th Ebola response in DRC, official health communication was mainly conducted in French, the national language used in official documents. As the response built its community engagement capacity, and actors placed greater emphasis on communicating with communities, the Ministry of Health and responders recognized the importance of Swahili as the most widely spoken language in the region. Subsequently, responders began to make information available in Swahili, the historic lingua franca of East Africa. However, the form of Swahili used in communication tools produced as part of the Ebola response was often a formal, international Swahili not understood by communities, many of whom spoke local dialects of the language or did not speak it at all. As late as September 2019, TWB research found that the response was still generating risk communications materials largely in French or Swahili.



TWB research highlights the importance of language in building trust

To aid the response, TWB's produced the following linguistic research:

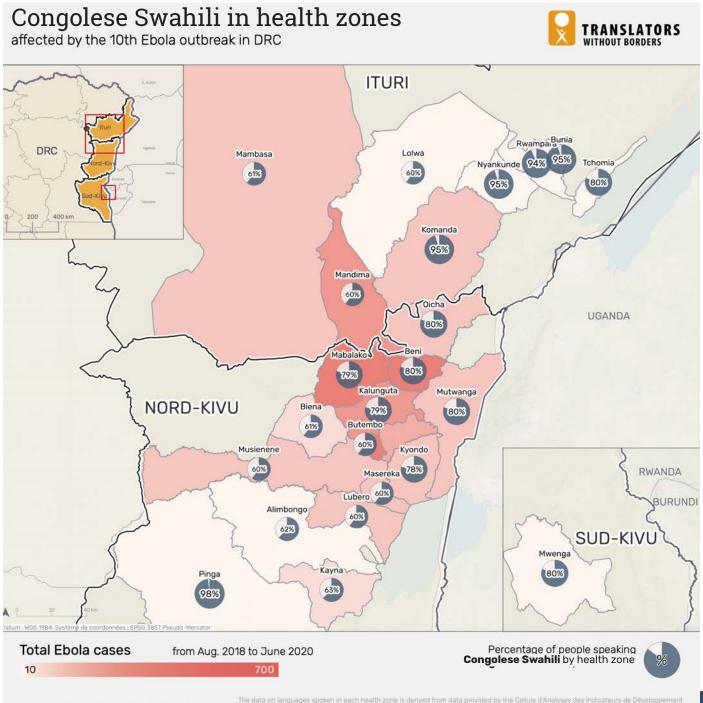
- A rapid language assessment in Goma, conducted in February 2019.
- Language mapping of the DRC.
- A <u>report on communication needs and preferences</u> in Beni, North Kivu, conducted in September 2019.

² Deborah Toppenberg-Pejcic, Jane Noyes, Tomas Allen, Nyka Alexander, Marsha Vanderford & Gaya Gamhewage (2019) Emergency Risk Communication: Lessons Learned from a Rapid Review of Recent Gray Literature on Ebola, Zika, and Yellow Fever, Health Communication, 34:4, 437-455, DOI: 10.1080/10410236.2017.1405488

Language diversity in affected areas

TWB's research showed that the form of Swahili used in communication tools produced as part of the Ebola response was often a formal Swahili that local communities could not understand.

TWB's analysis of existing data demonstrated that Congolese Swahili was spoken by a majority in the affected "health zones," as the DRC's health districts are known (map 3). Nonetheless, the percentage of people who speak Congolese Swahili in each health zone varies considerably, from around 60% in two of the most affected health zones of Mandima and Butembo, to over 90% in Komanda health zone and some of the less affected parts of Ituri Province.



Translators without Borders, September 2020.

The data on languages spoken in each health zone is derived from data provided by the Cellule d'Analyses des Indicateurs de Développement 2016 (caid.cd) at the Territory level. It was re-aggregated at the health zone level by area weighting the variables. This dataset is incomplete and often inconsistent. Statistics for percentage of the population who speak each language should not be seen as an indicator of fluency in that language. Health sites are from UNOCHA DRC. Ebola cases from WHO. Map 3: The spread of Congolese Swahili across health zones affected by the 10th Ebola outbreak shown against the number of cases in each zone. In all affected zones, there are people who do not speak Congolese Swahili and who need information in languages other than Congolese Swahili.

TWB's language mapping further highlighted the linguistic diversity of the affected areas. Although Congolese Swahili is widely spoken, many people, often the most vulnerable, do not understand it, excluding them from accessing important information and services.

Most spoken languages in health zones

affected by the 10th Ebola outbreak in DRC

Alim- bongo	Beni	Bienia	Bunia	Butembo	Kalunguta	Kayna	Komanda	Kyondo	Lolwa	Lubero
Nande 85 %	^{Swahill} 80 %	Nande 90 %	^{Swahili} 95 %	Nande 90 %	Nande 79 %	Nande 82 %	^{Swahlli} 95 %	Nande 80 %	Swahili 60 %	Nande 90 %
Swahili 60 %	Nande 76 %	^{Swahili} 60 %	Lingala 3 %	Swahili 60 %	^{Swahili} 78 %	Swahili 62 %	Lingala 5 %	^{Swahili} 77 %	Bila 20 %	Swahili 60 %
Piri 10 %	Mbuba 2 %	Piri 10 %	Kongo 3 %	Piri 10 %	Mbuba 18 %	Piri 10 %	Other 5 %	Mbuba 17 %	Bandaka 7 %	Piri 10 %
Nyanga 2 %	Bila 1 %	Lingala 2 %	Lingala 3 %	Lingala 2 %	Bila 7 %	Nyanga 3 %	Kongo 5 %	Bila 1 %	Lingala 7 %	Lingala 2 %
Mabalako	Mambasa	Mandima	Masereka	Musie- nene	Mutwanga	Nyankund	e Oicha	Pinga	Rwampara	Tchomia
Mabalako Swahili 80 %	Swahili	Swahili	Masereka ^{Nande} 90 %		Mutwanga Swahili 80 %	Nyankund Swahili 95 %	Swahili	Swahili	Rwampara Swahili 94 %	Nande 80 %
Swahili	Swahili 60 % Bila	Swahili	Nande	nene Nande	Swahili	Swahili	Swahili	Swahili	Swahili	Nande
Swahili 80 % Nande	Swahili 60 % Bila	Swahili 60 % Bila	Nande 90 % Swahili	nene Nande 90 % Swahili	Swahili 80 % Nande	Swahili 95 % Lingala	Swahili 80 % Nande	Swahili 90 % Nyanga	Swahili 94 %	Nande 80 % Lendu

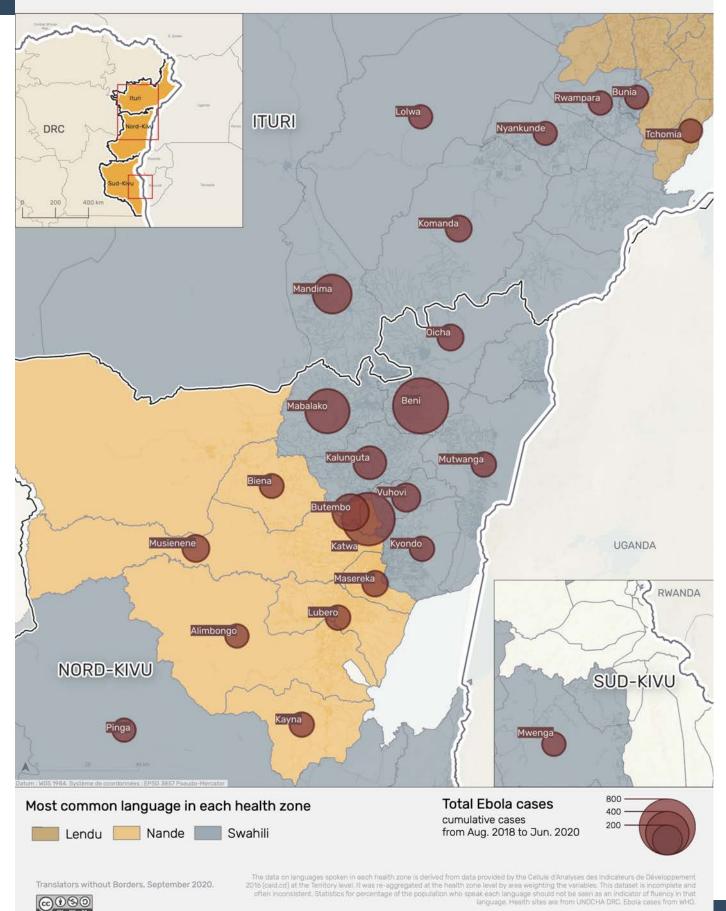
Figure 3: Languages spoken in health zones affected by the 10th Ebola outbreak. Some people do not speak the majority language at all and people often speak multiple languages to differing levels.

From the available data we can see that in many of the health zones which reported cases, the most widely spoken language was Nande, not Congolese Swahili. It is important to make information available in languages other than Congolese Swahili.

It is also important to note that the information available from government sources (Cellule d'Analyse des Indicateurs de Développement), as presented in Figure 3, does not assess the level of language spoken. It is therefore likely that many who are recorded as speaking the majority language of an area (often Congolese Swahili) will have lower levels of understanding, especially of written information and complex health information.

Language map of health zones affected by the 10th Ebola outbreak in DRC





Map 4: According to available government data, Swahili, Nande and Lendu were the most spoken languages in affected health zones.

How language affected risk communications

"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

As the epidemic spread further, reaching many more linguistic groups, language issues became increasingly pressing and the response more complex as it expanded to cover larger areas.

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

Research participant feedback from TWB's Beni report.

Rapid needs assessment in Goma

TWB conducted a rapid information needs assessment in Goma, at the request of response partners. This aimed to determine how well communities understood risk communication materials and to provide partners with recommendations on navigating the linguistic environment.

Our assessment showed that, in Goma, many people did not understand the risk communications materials they had received.

Most focus group participants did not understand apparently simple French words such as sanglant (bloody), sperme (sperm) or gencives (gums). When asked the equivalent Congolese Swahili word for "gums," focus group participants could not agree. The standard Swahili word, which participants did not suggest, is ufizi. The term used in local Swahili is nyama za mumeno (literally, "meat of the teeth"). Focus group participants were most comfortable with bihanga, a term the local form of Swahili adopted from the Hunde language.

TWB also tested comprehension of the first page of the vaccine informed-consent form for adults in Swahili and French. TWB assessed the Swahili form as being written in a mix of highregister Congolese Swahili and standard Swahili; it also contained words in French and English. All participants had difficulty understanding these forms, especially where they contained technical or unfamiliar words in standard Swahili, French, or English. They highlighted words they did not know.

Seemingly basic words such as fomu (form) or critical concepts such as ridhaa (consent) or chanjo (vaccine) in standard Swahili caused confusion. In particular, women over 35-years old did not understand chanjo. They said that ndui, which refers specifically to prenatal or preschool vaccines, was more familiar to them. Conversely, half the men were unfamiliar with the term ndui. Respondents recommended translating the form into local languages.

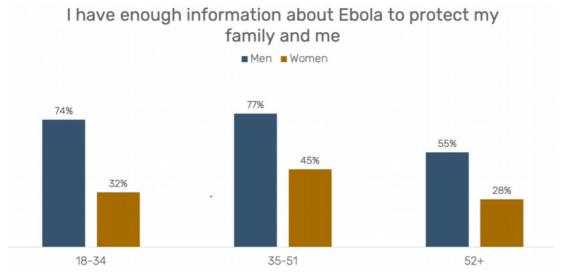


Figure 5: On average, women and older people felt less informed about Ebola. They also scored lowest for comprehension of Ebola information in all languages and formats.

Average comprehension rates by language and format

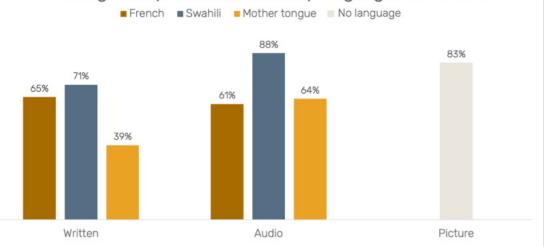


Figure 6: Eighty-eight percent of respondents understood audio information on Ebola in Congolese Swahili. Eighty-three percent understood pictures with simple messages, and 71 percent of respondents understood written information in Congolese Swahili.

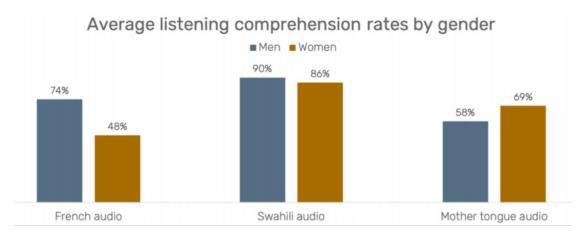


Figure 7: Women, unlike men, understood an audio message in their mother tongue better than they did in French.

Source of graphs: TWB, "Missing the Mark," rapid language needs assessment, Goma 2019

From this rapid assessment in Goma, presented to partners and to the DRC's Ministry of Health, TWB found that women and older people were more likely to need information in local languages. On average, women and older people felt less informed about Ebola. They also scored lowest for comprehension of Ebola information in all languages and formats.

Linguistic assessment in Beni

Building on the initial assessment in Goma, TWB spoke to more than 200 health communicators, patients, and residents in eight health zones in Beni, North Kivu, to more closely examine the dynamics of languages in the intervention. This second piece of research showed that three factors particularly limited the effectiveness of communication:

- The language and terminology used
- The content provided
- The channels of communication used.

People reported that they wanted complex and transparent information in a language and style that was familiar to them. They wanted in-depth explanations that related to the latest developments. Yet health communicators often lacked communication tools and training adapted to these developments, and struggled to provide clear and consistent answers. The resulting misunderstandings and contradictions confused people, and the lack of detailed explanations created further doubt and frustration.

People placed more trust in information they received through face-to-face communication. This format gives them an opportunity to ask questions. Our research suggests women in particular prefer to receive information from someone they know and trust. Local health communicators who are aware of cultural sensitivities can relay information more effectively. People want to hear from experts who know how to communicate clearly with them.

This research also highlighted the central importance of language in building trust with communities, which was significant in the context of community mistrust and violence against responders. TWB research found that speaking in local languages established trust between health communicators and the community.

"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

The research also highlighted the struggles of health communicators who lacked the tools to properly address communities' questions and needs.

"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

This research highlighted the fact that when affected communities didn't receive information in a language they understood, they reported being less likely to seek health care, fearing misdiagnosis and miscommunication.

Language matters most when we talk about disease and death

Language affects whether a message and the messenger are trusted and believed. When health communicators in crisis-affected eastern DRC deliver risk communications in a language that local communities do not fully understand, they prompt distrust and fear – especially when they cover sensitive topics like health and dying.

TWB's research in Beni showed that participants didn't understand key medical concepts and seemingly simple terms in French and standard Swahili. Vulnerable populations, including women and older people, needed information in localized Nande. It is important to have information about which languages are spoken in affected areas, and to understand how access to information of vulnerable groups is impacted by language and literacy levels.

"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

Some health-related terms are socially and culturally unacceptable, particularly those connected to death and dying. People consider some words harsh and offensive. To avoid using certain terms that many people consider harsh and offensive, health communicators created euphemistic explanations to share key messages. These alternatives were often more acceptable because they placed the patient at the center of the communication – speaking of 'healing' rather than 'treatment', for instance. But at times they were also inconsistent and vague, and could lead to misunderstandings.

Participants said they preferred to get these messages in the local language from a native speaker, a reflection both of generalized skepticism about outsiders and of a desire to obtain information they could understand.

Beyond the declaration of the end of Ebola



Thanks to advances in vaccination and care, the 10th Ebola outbreak in eastern DRC saw more survivors than ever before. Survivors will continue to require medical and psychosocial support well beyond the end of the epidemic. Work to support survivors, to identify and address potential relapse cases, and to address stigma and protection concerns must continue to take language into account. Research and testing on preferred and non-stigmatizing terminology should continue, especially in relation to survivors of Ebola.

Section 3

Lessons and tools for the 11th Ebola outbreak and future epidemics in DRC

While TWB's research findings have clear applications in the 11th Ebola response and beyond in DRC, many of them can also be more broadly applied to other public health crises. Organizations involved in responding to crises can increase their impact and reduce harm with these eight recommendations:

Eight recommendations for more effective communication against Ebola virus disease and other health crises:

1 Include language data in early assessments and surveys. To identify the most effective languages, formats, and channels for communicating on difficult concepts such as health, disease and death, organizations should include four language questions in needs assessments and surveys.

2 Use the local language for all oral or written risk communication on the risks of Ebola virus disease. It is essential that stakeholders prioritize communication in these languages, to ensure that affected people understand key messages. French alone is ineffective and confusing.

3 Test the understanding and communication preferences of residents of areas affected by or at risk of Ebola virus disease. Testing the language comprehension of an affected population is the best way to determine which languages to use; often people underestimate or overestimate their comprehension of a language when asked. Education levels in Goma, for example, are relatively high, and linguistic diversity relatively low compared to other affected or at-risk areas. For the 11th Ebola outbreak, the response will need to be equally localized to identify effective languages and formats for communicating Ebola virus disease risks with affected populations elsewhere in DRC.

4 **Develop information materials in plain language**. It is essential to explain concepts using familiar words and a clear sentence structure. Technical jargon and words that are not commonly used should be avoided. It is important to ensure that the content is field-tested, accurate, in context and appropriate and that it addresses the main concerns of communities.

5 Use terms consistently. Community-facing responders need to communicate in a coordinated fashion and use the same words and phrases to describe concepts. This means going beyond a generic message bank and engaging in active quality control of risk communication efforts. Inconsistency leads to misunderstanding.

6 **Localize translation of national languages.** Congolese Swahili and other national languages use grammar, sentence structure, and words borrowed from local, other national, and foreign languages. They are used to varying degrees depending on the locality. Stakeholders must therefore develop and test their material as locally as possible to ensure clear communication.

7 Place audio formats at the heart of communication strategies. In addition to wordof-mouth, loudspeakers and radio can be effective in relaying messages to communities who prefer oral communication. In DRC, our research suggests that medical staff and Ministry of Health officials can be trusted spokespeople for delivering information orally. ⁸ Use audiovisual formats to further facilitate understanding. Visual content should be simple and culturally relevant. It should be developed in partnership and pretested with local residents to ensure that the messages are understood. Audiovisual formats like mobile cinema and community theater can also be helpful. Narration or captions can increase comprehension.

Recommendations from "We need to talk: Effective Ebola risk communication requires respect and transparency and remains as vital as ever"

TWB tools and resources for responders in DRC

We help provide information in languages and formats people understand and prefer. TWB has built and trained a network of linguists in DRC languages, with particular focus on Congolese Swahili and Nande. We provide language services including written and audio translation, transcription, plain language editing and training, and pictorial communication and information design. Since the beginning of the 10th Ebola response in DRC, the <u>TWB</u> <u>community</u> of volunteer linguists, who by September 2020 numbered 104, has translated more than 350,000 words in Congolese Swahili, Nande, French, Lingala, and Kinyarwanda.

We help create more strategic risk communication strategies grounded in language data. TWB has produced language maps for DRC, North Kivu, and Equateur covering more than 30 languages. These maps are an important tool in advocating for language-sensitive approaches, but quality language data is critical to improving our mapping efforts. TWB works with partners to access networks on the ground to aid in data collection and research on gaps in language and communication – helping to build critical language maps to support the response.

We offer a language tool kit to help health workers communicate. Drawing on the expertise of these linguists, and field testing with partner organizations, TWB created a toolkit for health communicators that includes communication guides on Ebola, health, terminology and grief.

We build glossaries to ensure consistent and accurate communication. TWB has developed and regularly updates a <u>DRC health glossary</u> that includes more than 400 terms related to Ebola, COVID-19, and health in Congolese Swahili, Nande, Lingala, French, and English, with more languages planned. The glossary is available online and offline through TWB's glossary web app.

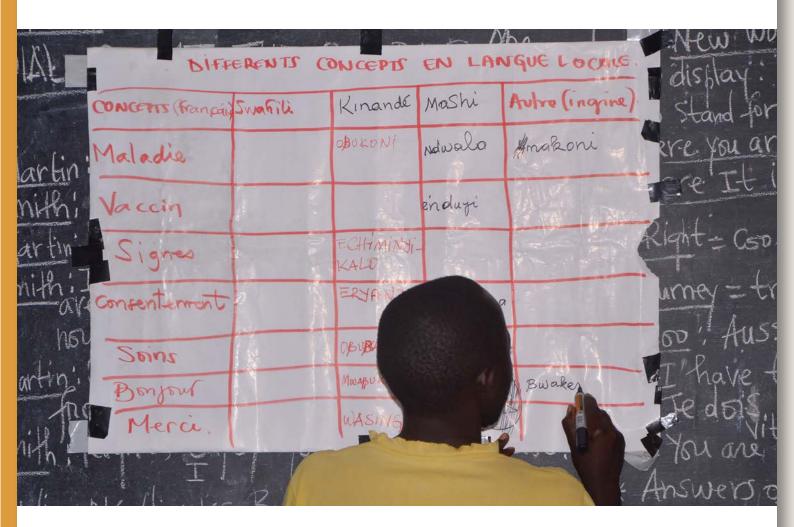
We build local staff capacity to communicate complex concepts in local languages. TWB provides training and workshops for health communicators and humanitarian responders in language, communication and terminology.

About TWB

Translators without Borders (TWB) is a non-profit organization offering language and translation support for humanitarian and development agencies, and other non-profit organizations on a global scale. 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

TWB has been researching language barriers in health responses in DRC since early 2019. We supported the response to the 10th Ebola outbreak in eastern DRC, and are currently supporting the response to the 11th Ebola outbreak in Equateur province, as well as the COVID-19 pandemic response. We believe communication challenges like those identified in our research on the 10th outbreak affect the reach, impact and accountability of humanitarian action in DRC beyond public health emergencies.

For further information on the importance of language in the DRC response to health crises, visit our <u>webpage</u>. Contact <u>DRC@translatorswithoutborders.org</u> to find out more.



The maps presented in this report were produced using data from the 2016 Development Indicators Analysis Unit. The data was transposed and adapted to the scale of health zones (UNOCHA DRC) through geoprocessing routines. Data on the number of Ebola cases was drawn from WHO datasets, and the location of Ebola Treatment Centers was based on mapping produced by the EU Emergency Response Coordination Centre (ERCC).



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Ministry of Foreign Affairs

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