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VACCINE

Why vaccine inequality is our biggest
COVID-19 communication challenge yet



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INTRODUCTION & ACKNOWLEDGEMENTS

The pandemic continues to highlight that while the virus has touched almost every corner of the globe the impact has been far from uniform. As rich countries receive enough doses of vaccines to protect their citizens several times over, countries in the global south must contend with the reality that very few in their population will get close to a needle in 2021.

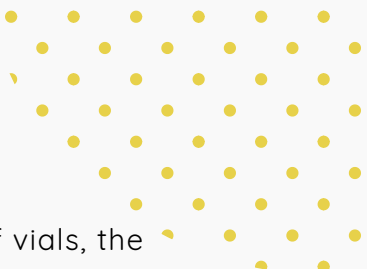
It is this inequity of access and the communication challenges that it poses, that we will explore in this paper. We question how we can split our focus to, on one hand, engage with communities to ensure they understand how vaccine prioritization will be made, to also then manage expectations of access, while still addressing the perception that the pandemic is over when vaccination begins?

Since mid-2020, the Rooted in Trust project has been funded by the USAID Bureau of Humanitarian Assistance (BHA) to collect, analyze and respond to COVID-19 rumors and misinformation in seven humanitarian contexts – Afghanistan, Central African Republic, Mali, Sudan, Lebanon, the Philippines, and Colombia. Each of these contexts has given us the opportunity to witness differing approaches to vaccine access and distribution as well as communication practices in relation to the vaccine – and how they have been received by the countries in which we’re working.

There is no argument that universal, and equitable, access to a safe and effective COVID-19 vaccine is critical to ending the pandemic. More than two-thirds of the world’s nations have signed up to either contribute to or receive vaccinations from [COVAX](#) - an effort from the Gavi alliance that promises to provide a lifeline to lower-income nations that would otherwise not be able to afford to buy vaccines for their citizens. By December, [Gavi COVAX AMC](#) had [secured enough funding](#) to target up to 20% population coverage for [92 low-middle income economies](#).

“THE WORLD IS ON THE BRINK OF A CATASTROPHIC MORAL FAILURE – AND THE PRICE OF THIS FAILURE WILL BE PAID WITH LIVES AND LIVELIHOODS IN THE WORLD’S POOREST COUNTRIES.”

Dr Tedros Adhanom Ghebreyesus
WHO Director General



This contrast in accessibility has politicized the vaccine, with the promise of vials, the newest tool of soft-power diplomacy. Vaccine-producing nations like China, Russia, and India are handing out millions of doses of vaccines to strategic allies before everyone in their own population has received a dose. And while both efforts will importantly contribute to helping the world's most vulnerable gain access – we are unlikely to see anything close to universal coverage in 2021. The growing divide has also been referred to as a modern ‘vaccine apartheid’.

In the following pages, we explore what we see as some of the major challenges risk communicators will face in communicating about vaccines in complex contexts. On the final pages, we offer some recommendations for the way forward. As always, we admit we do not have all the answers. Some of the solutions proposed may feel familiar and yet are still not common practice. Because even agreeing on good practice does not make it easy to implement. Others will be hard, sometimes uncomfortable, and may prompt wider discussions in your organization as to what our role should be as risk communicators in this pandemic.

Irene Scott, Global Project Director, Rooted in Trust

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Authors:

Irene Scott, Julie Langelier, Rocio Lopez Inigo, Emily Cowlrick, Ida Jooste, with support of the Rooted in Trust team, the Internews Health team and editorial guidance from Meghann Rhynard Geil and Stijn Aelbers.

In the process of writing this paper, we have consulted a number of public health and risk communication experts, both within Internews and at many Non-Government Organizations, UN agencies, and academia.

Just as the solution to the pandemic will be made of the collective efforts of many, we too wanted to draw on the growing risk communication expertise to ponder the communication challenges that lie ahead.

We appreciate everyone in this hive mind who gave their time and lent us a vial of their expertise in the development of this paper.

Special thanks to representatives from UNICEF, the World Health Organization (WHO), International Federation of Red Cross and Red Crescent Societies (IFRC), International Organization for Migration (IOM), the Communicating with Disaster Affected Communities Network (CDAC), Health Gap, The UN Refugee Agency (UNHCR), READY Initiative/Johns Hopkins Center for Communication Programs, Global Common Society International (GCS), BBC Media Action and Anthrologica for lending us their time and expertise to create this report.

COMMUNICATING UNCERTAINTY:

When ‘I don’t know’ is the best there is

Throughout the crisis, public health responders, scientists, media, and government officials had to provide guidance and communicate with high levels of scientific uncertainty. This has manifested through a lack of clear data or knowledge, or through divergent and contradictory views from experts - even within the same science cohorts. Information and public recommendations have been continuously updated, creating confusion among people on what measures to follow, and which voices to listen to and ultimately - what to do to keep themselves and their families safe.

Experts were initially unclear whether asymptomatic people were carriers of the virus, which affected the level of isolation and disruption to daily activities people needed. Similarly, the unclear guidance on the use of masks in the beginning of the pandemic, the lack of clarity on their efficacy to control the virus continued to leave space for populations across the world to doubt legitimate voices. Amidst the confusion, people turned elsewhere, often to less reputable sources who gave definitive (but unreliable) advice and information or used the uncertainty of governments and health experts as evidence of a greater conspiracy.

In the “post truth” era where facts are increasingly contested, a common assumption is that communicating uncertainty will reduce public trust. Communicating when the message is not clear makes most risk communicators very uncomfortable. It is drilled into communicators from early on that for the public to accept a public health directive, information must be clear, consistent, and realistic.

And we have seen repeatedly in the contexts where we are working, an unwillingness from many organizations to communicate about the vaccine or to engage with the communities’ questions until there is certainty. It is true, that when health messaging is vague, inconsistent or unrealistic, it engenders the kind of confusion, and misinformation that erodes trust.

But people do not just stop asking questions when we refuse to respond. In a pandemic, you cannot wait until you have all the answers. You need to communicate and find a way to become comfortable with the grey areas, and to take the community on that journey with you.

We have identified several areas across our research that deserve attention when responding to these questions and addressing communities in need of information amidst increasing uncertainty:

Uncertainty is part of the crisis and we cannot avoid it: COVID-19 has resulted in a continuous adjustment of people’s daily lives, decisions and behaviors.

We need to accept the uncertainty that comes with this. No one has all the answers. We are learning as we go. We need to be clear, but also communicate our limitations each step of the way.

What we know and what we do *not* know: Ignoring hot topics because we do not know the answer will only allow further space for misinformation as communities attempt to fill the information vacuum with other sources.

Our feedback data in Afghanistan shows that in late December 2020, when Pfizer-BioNTech and Moderna vaccinations were already being distributed in some countries in the Global North, communities in Afghanistan were still questioning the existence of vaccines for COVID-19. Yet, the lack of clear plans for vaccine rollout kept many humanitarian partners silent about next steps, waiting for clear guidance from public authorities. Similarly, in Mali, some humanitarian organizations chose to delay conversations on COVID-19 vaccines with journalists until public plans were announced. Meanwhile, fears about the upcoming vaccines conflated with misinformation on routine immunization services for children, triggering parents across several settings to question and confront vaccination campaigns for polio or measles among others.

Communicating on what we are doing to fill information gaps will help reduce stress and anxiety: Become comfortable in explaining why you don't have the answer and what you will do, or when you may be able to answer questions in the future. Manage expectations through transparency to build trust.

“

Has confinement stopped contagion? No. Have masks stopped contagion? No. Does the vaccine cause a person to be completely immune? No. If vaccinated, can you stop wearing the mask? No. Is the vaccine completely safe? No. But everything indicates that the world population must be vaccinated and governments keep silent and obey...no more!

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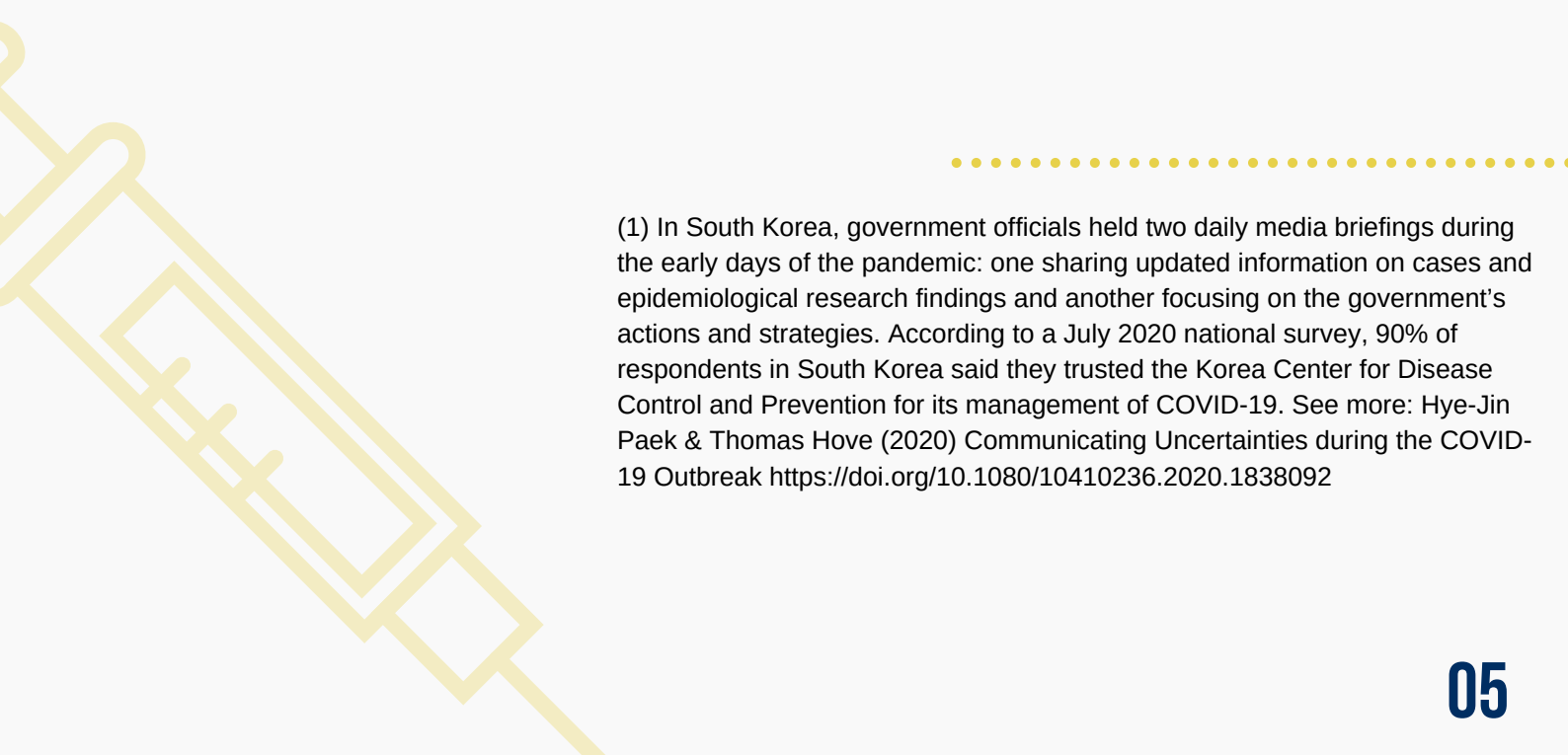
- Rumour data collected in Colombia

Making people co-participants in the conversation, and providing regular updates on what actors are doing, has proven successful in this pandemic.⁽¹⁾ Several humanitarian informants working in Eastern and Western Africa confirm that showing action and making communities aware of the organization's plans at the community level has helped in previous public health responses to build trust. Managing expectations on what can be achieved and how it will be achieved is important as we engage in the dialogue.

It's also important to be open about the risks involved in vaccinations. All vaccines come with a risk associated with them. It might be a very small risk or a very slight side effect, but to sugar-coat the risk, or to avoid discussing it entirely, could be perceived as lacking transparency and affect the trust relationship with your community. Mistrust opens the door not just to confusion but to weaponized disinformation, and this will prevent people from taking a vaccine that they need.

We have already seen in this pandemic instances of the misinterpretation of the risks associated with vaccines. When reports came out of Norway that 30 patients had died after being injected with the Pfizer/BioTech vaccine, many on social media jumped to the conclusion that the vaccination was dangerous or even deadly. While in the days that followed it became clear that the deaths were related to particularly elderly and frail patients, the clarification did not spread as widely as the initial news.

Research in the Journal of Psychological Science shows that when people are physiologically aroused, due to a strong emotion, for instance, the autonomic nervous is activated, which then boosts social transmission. Simply put, we are more likely to share information that produces a strong emotional reaction. If we are prepared for the risks of vaccinations, and we are able to weigh those risks against the risks of avoiding vaccination, we may be less likely to share so readily when these stories emerge.



(1) In South Korea, government officials held two daily media briefings during the early days of the pandemic: one sharing updated information on cases and epidemiological research findings and another focusing on the government's actions and strategies. According to a July 2020 national survey, 90% of respondents in South Korea said they trusted the Korea Center for Disease Control and Prevention for its management of COVID-19. See more: Hye-Jin Paek & Thomas Hove (2020) Communicating Uncertainties during the COVID-19 Outbreak <https://doi.org/10.1080/10410236.2020.1838092>

VACCINE HESITANCY:

Why increasing acceptance is a growing challenge

At the root of vaccine-related misinformation lies not only mistrust and fear, but also legitimate questions and doubts that do not yet have clear responses. A year after the initial outbreak, communities feel an increasing loss of agency and a strong mistrust in government, pharmaceutical companies, politicians, and public health actors is apparent.

As vaccines became a tangible reality, the rumors increased. From the period of August-October 2020, Internews' Rooted in Trust teams collected just 110 vaccine-related rumors. However, in around the same period, between November 2020 - January 2021, we collected over 700 rumors. This 6-fold increase in rumors corresponds to the first positive clinical trial results, and the approvals for use that followed. Government-approved rollouts of vaccines also began in 52 countries toward the end of last year and we now see approximately 2.85 million doses administered a day globally, however, the delays in low-income countries are stoking fears, discontent, and rumors related to equal access, manufacturing, supply, acquisition, distribution, inoculation, and herd immunity.

Vaccines are some of the most efficient public health tools for reducing the burden of infectious diseases, but of course, not everyone is rushing to get in the vaccine queue. Even with detailed rollout plans, and access to the sought-after vials, there are likely to be some people within your community who either want nothing to do with it - or who are still not sure.

This category is often described as 'vaccine-hesitant. According to Johns Hopkins, only 63 percent of respondents across 23 countries will accept a vaccine. That is well below the 75 percent minimum estimate public health experts have recommended for a population to reach "herd immunity".

There can be several reasons for this hesitancy. Someone may perhaps be influenced by previous poor experiences of healthcare, government, or health authorities, long-held beliefs about health, misinformation, or legitimate questions about the product itself. The speed at which vaccines were developed and some uncertainty over the long-term impacts, or their ability to prevent transmission or combat new variants of COVID-19, continue to drive rumors related to vaccines in all contexts.

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Do not get vaccinated!!!! The vaccines are not safe (a lot of serious side effects and in addition they are useless, the epidemic is OVER, it is the leaders that keep it going because they receive a commission on vaccines!!!! Wake up!!!!

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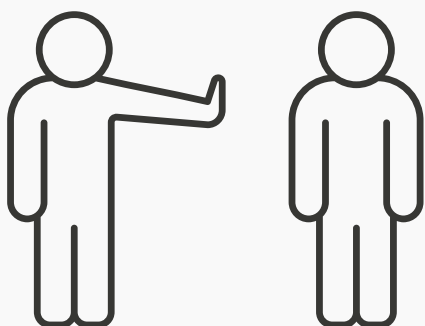
- Rumour data collected in Mali

In the Philippines, significant levels of vaccine hesitancy can be attributed to the impact of the Dengvaxia controversy, which has reduced trust in vaccines from as high as 90 percent in 2015 to a low of 60 percent just before the COVID-19 pandemic hit. In Lebanon, vaccine perceptions are heavily impacted by rumors being shared from abroad, namely videos and accounts of severe side effects from countries further along in the vaccine rollout than Lebanon.

This was a key point of hesitation for most Syrians interviewed in our Information Ecosystem Assessment and is a common point in our rumor database. In Afghanistan, Lebanon, Colombia, and the Philippines we have collected several 'experimentation' rumors - where people claim the vaccines are being 'tested' on them.

In Mali, the mistrust in the vaccine comes from a lack of trust in health authorities and the transitional government, who are regularly accused of financially benefiting from the pandemic. Similarly, in Colombia, one of the most common rumor themes relate to COVID-19 being a hoax, and the vaccine rumors follow naturally from this belief. Close to 20% of our rumors talk about the vaccine as a method of government control of the population, that the immunity from the vaccine doesn't last and that if masks are still necessary after the vaccine it's because the vaccine doesn't work.

Rates of hesitancy towards vaccines, in general, have been growing worldwide in recent decades, however, this hesitancy is usually in reaction to childhood immunizations. What makes this hesitancy different is that adults (especially those in high-risk professions) are likely to be the first priority to receive the vaccine. This is not adults deciding on behalf of their children, but for themselves, and this may trigger a different emotional reaction to the decision-making process.



Additionally, in many humanitarian contexts, there is the challenge of what can be described as 'vaccine indifference'- where people have so many competing challenges that the pandemic and the impact of a virus, just does not rank highly in their list of concerns. This is a narrative we've heard echoed in many of the contexts where we are working. 'Why should I care about COVID-19, if I don't have a job/running water/access to education?' Or, why should I care about this virus when there are more concerning health crises on my doorstep (Ebola for example)?'



Differing communication strategies will be needed to address the different motivations behind vaccine indifference or hesitation in our contexts. Studies have shown that simply correcting myths about vaccines not only fails to improve intention to vaccinate but also may backfire and decrease intention to vaccinate³. By understanding the motivation behind the hesitancy, we can create communication approaches that speak to that motivation, match the reality of the receiver and do more than simply replacing rumor with 'fact'.

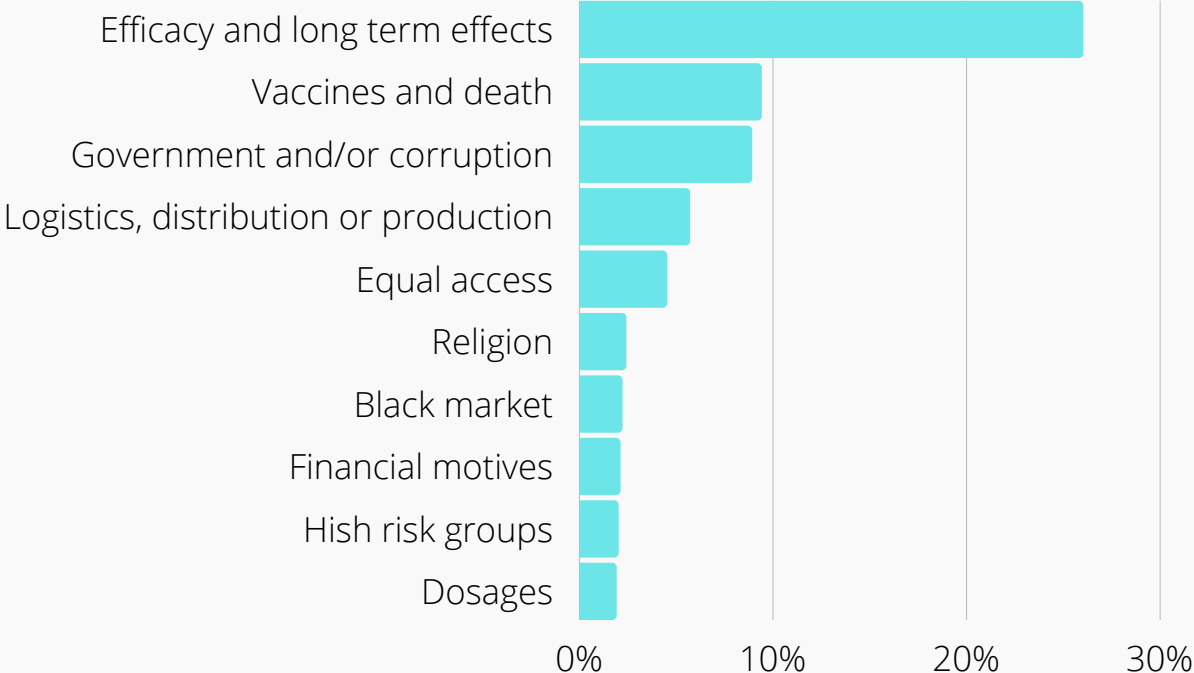
We need to ensure that there are communication channels available that are accessible and adaptable to many in the community to allow them to ask questions and receive information about the vaccine and the vaccination process.

The community needs to feel reassured that asking questions is important, encouraged, and key to having the quality information you need to make the decision. Because it is a decision after all. No country to date has legislated to make taking any of the COVID-19 vaccinations compulsory. If people feel the vaccine is being forced upon them, and that they have no agency in the process, then we play into the narrative perpetuated by some disinformation advocates and conspiracy theorists that the pandemic, or the vaccine, is a tool of ‘control’.

People also need to feel comfortable that when they ask a question, they will not be labeled as an ‘anti-vaxer’ or any of the other derogatory terms that are sometimes associated with questioning vaccines and their impact. In her recent book ‘Stuck – How vaccine rumors start and why they won’t go away’, Professor Heidi Larson writes that when people are trying to make sense of uncertainty, feeling suppressed or censored can have the opposite effect. Disinformation campaigns often work by identifying and fostering a ‘seed of doubt’. Sow enough doubt, and people start to lose trust in previously trusted information sources. People may conclude that the safest bet is to be cynical, believe no one, and stop asking questions.

Consider vaccine hesitancy as a starting point for respectful discussion and be open to discussing the risks and challenges as well as the individual and community benefits. We need to open our communication channels, devote time (and money) to ensure they are well staffed, can meet the needs of the public, and are adaptable to the different stages of the vaccination process and the corresponding changing information needs.

More than 700 vaccine related rumors were collected as part of the Rooted in Trust project between August 2020 - February 2021 from Sudan, Mali, Colombia, Central African Republic, Lebanon, the Philippines and Afghanistan. The below graph provides an overview of the Top 10 sub-themes and its prevalence across our data. For country-level analysis of vaccine rumors, please visit: <https://humanitarian.internews.org/rit>



SHOOTING THE MESSENGER:

The power of a trusted voice

It's commonly accepted that who delivers information about COVID-19 and the vaccine matters – perhaps more than the quality of the information itself. Factual information delivered by someone you don't trust will not sway your opinion, but inaccurate information delivered by a trusted source could be very influential.

We know this - and it's been at the heart of many discussions about the Infodemic in the last year. But what we have found in the course of our research, is that it's not just that different sections of society trust different information sources. But when people are looking for health information, they may trust different sources compared to when they may be seeking other forms of vital information. Our trust relationships are not homogenous within a community, nor are they static.

Proximity matters and has an important impact on trust and influence. In most contexts, our research showed that the closer the source of information was to the receiver, the greater the increase in trust towards that information. People trusted community health workers, local doctors, and traditional medicine providers far more than they trusted Ministries of Health and in some circumstances, information coming from global bodies such as the WHO.

While geographic proximity is sometimes central, proximity can also mean shared language, shared belonging or peer status, and other markers of closeness with the community. External actors that hold long-standing physical presence in the community can come to be perceived as proximate. For instance, in Lebanon, Syrians have grown frustrated with the stop and go nature of humanitarian support and local and international charities with a physical presence where

interviewees reside were more commonly referenced as a trusted source of information than official sources that did not have a direct presence in the community.⁽⁴⁾

Factual information delivered by someone you don't trust will not sway your opinion, but inaccurate information delivered by a trusted source could be very influential.

One of the community representatives interviewed during the [Information Ecosystem Assessment research in the BARMM region of the Philippines](#) told us, “I trust my ulama (religious leader) over WHO”. Unlike the rest of the Philippines, where health experts and WHO are the most trusted sources of COVID-19 information, people in BARMM trust people with proximity or personally known to them – religious leaders (80%) and other community leaders (78%).

In Lebanon, our research found that Syrian refugees particularly tended to trust those that had a physical presence in the community. So, for example, Syrian NGOs and local health providers were more trusted sources of information than the Ministry of Public Health.

(4) For more on our findings around trust during the pandemic, see our report: [Confidence, hesitancy, or resistance: Unpacking trust in the light of the COVID-19 pandemic in fragile contexts](#) ([link](#))

We saw similar trends with IDPs in Mali, and with migrants in Colombia where only 12% of respondents felt absolute trust in the information provided by the national government compared to 49% feeling absolute trust in community health workers.

One reason for this could be the quality of the information that communities received, especially early in the crisis. Information was often generic and did not fit the reality of the receiver. Tone-deaf messages about social distancing and staying at home in contexts where the living conditions or economic reality made those actions impossible. Or messaging that suggested to refugees to wear face masks, use hand sanitizer – when none was available – contributed to the feeling that this information was not intended for them, further playing into early rumor narratives that COVID-19 was a ‘rich person’s virus’.

This trust in these local information providers puts incredible pressure on local healthcare systems that did not always have answers to the questions their community was asking. This resulted in trusted sources providing less than trustworthy information and inadvertently contributing to the spread of rumors. Between October 2020 and February 2021, we tracked more than 70 rumors posted on social media by healthcare workers with a reach of 52 million followers, 528 thousand reactions, 25 thousand comments, and 111 thousand shares.

This complex relationship between trust, influence, and behavior change further highlights the need to continually listen to our audiences, understand these dynamics and support trusted and influential information providers. **And this may mean forging new relationships.** The local community leader whom you have worked with to disseminate other information within a community may not be a great choice for disseminating information related to the pandemic, and ‘social influencers’ who may have the power to sway public opinion, may not also hold the same power in every instance. For example, [rumor data collected by the project](#) identified that often, once influential people, celebrities, politicians, government officials contract the virus, there is an almost immediate uptick in social media activity and rumor production related to the hoax theme. Rather than having a positive effect on local communities to practice public health best practices, the infection of public figures triggers a backlash among young people to deny the virus’s significance.

“When we talk about COVID- 19, community members consider us the people benefiting from the Coronavirus funding”

- Radio station manager, South Sudan

Trust is not static. It has shown important for community outreach workers and media partners to avoid concentrating solely on COVID-19. In contexts where the outbreak may be competing for space with a variety of other challenges, a barrage of communication is likely to feel tone deaf. In several contexts, media engaged in the COVID-19 response faced criticism for focusing on the disease. A radio station manager in South Sudan said: “When we talk about COVID- 19, community members consider us the people benefiting from the Corona virus disease funding”. Similar accusations were made towards health workers and institutions in Mali and Lebanon as it brings funding from international donors.

Build constant capacity among community volunteers, outreach workers – they need to be able to respond to the questions that fall through the cracks: Learning from the DRC Ebola ring vaccination in 2019, the 2 vaccines brought their load of rumors. During the Ebola vaccine roll-out in DRC, the strategy changed, and messages were not updated fast enough at the country level. As it happens in many contexts, the messages had to be cleared by government actors who were slowing down communications. Outreach workers and traditional health responders are at the forefront

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The tetanus vaccination campaign taking place in CAR is actually a test of COVID-19 Vaccine

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- Rumour data collected in CAR

and must answer questions from the community beyond the key messages. To do so they need to be updated with the latest information on the vaccine including insights around roll-out and supply. Forefront communicators and responders should be involved in developing answers to evolving questions and concerns and regular briefing and information-sharing sessions should be organized.

Aiming at a Community-led response - Community engagement should go beyond communicating through people paid by the response and popular social influencers. Humanitarians should engage with trusted local structures and support the community’s effort to end the disease. The person who explains the details around vaccines should be from the same community using the right language. When a neighbor is involved in a committee, it creates interest and trust within the community.

Based on IFRC experience in Latin America, civil society groups, committees, and individuals have shown interest to part take in vaccination plans. According to the Rift Valley Institute, in a sub-Saharan context,

“The people who decide what happens when an infectious disease strikes a neighborhood are generally those who play a role in treatment pathways, and who have extensive experience in fighting epidemics. These include women running households, elderly medically experienced women, herbal experts, local chiefs and elders, cattle camp leaders, pharmacists, faith leaders, and spiritualists, depending on the local societal organization.”

The community leaders in the traditional health care system and local health providers should be supported and embedded in the response, not only used to pass key messages designed by experts.

COMMUNICATING PRIORITY:

Who, what, when where?

One of the main challenges is talking to communities about the timeline of when they can access the vaccines. Discussing details on *who* will get the vaccine and *when* they will get it are important for communities, to understand selection criteria and to manage expectations. Yet, the *why* is a burning question that is less commonly addressed and it's vital to manage expectations but also to ensure that Humanitarians are not seen as gatekeepers – the person standing between the community and the vaccine.

The hyper-connected world that we live in allows people to access information, not only from their immediate local reality but also from far-off places online. This can bluntly highlight the inequality in access to vaccines, not only within the country but at the regional and global levels. The artificial scarcity of vaccines could contribute to community anxiety or a feeling that the pandemic is 'less relevant' in their context. In fact, rumor data from our Rooted in Trust project suggests that conversations on vaccines across most of our humanitarian contexts peaked in December 2020 when vaccines began to roll out in the United States and Europe. This illustrates that communities are not isolated and are increasingly part of transnational digital conversations.

In an ideal world, the decision of prioritization of vaccine access would happen with community consultation. Ensuring that there was a level of community engagement, consensus and understanding as to why some people should access vaccinations before others. We know, that in a pandemic, this is unrealistic. But because the community is having their priority status decided for them, there is the likelihood that the process could feel disempowering, people may feel hard-done-by, or not understand why they are missing out.

This potential community anger or confusion that can come from a lack of understanding about how these decisions are made could once again play into the narratives of government control that have often appeared in our rumor data.

To allow the community to feel part of the process, and to ultimately support the decisions that have been made on their behalf, it is crucial to ensure there are channels to explain how these decisions were made. Explaining how these decisions of prioritization are made is key – explain what “vulnerable” means, who decides who is vulnerable and how.

While involving the community in deciding priority might not be possible, the community can play a role in designing the communication channels and products that discuss prioritization and the rollout plan. There is no reason why these can only be designed by distant committees and communication experts. Look for opportunities where the community has channels to contribute and regain some agency.

Questions on global distribution, agreements with international organizations and access through COVAX facilities or the issue of vaccine donations, purchases and manufacturing may be too complicated for many communities to make sense in their local reality. Yet, communication should not be halted, and the uncomfortable questions must be responded:

· **If they are not going to get it, they better know about it:** Discussing the lack of access or unavailability of the vaccine must be encouraged to avoid additional frustrations, fraud or risk to vulnerable populations. To this regard, a humanitarian and health communicator working in Afghanistan explains how despite the lack of clarity on the arrival of quality vaccinations and rollout plans in the country at the end of December 2020, rumors on the availability of ‘European’ vaccines in corner shops were getting traction among people. “The little access to information and technology in hard-to-reach areas draws a fantastic opportunity for self-declared health experts that take advantage of communities’ tensions, confusions and knowledge”, she explains. This information vacuum is easily filled by misinformation that poses additional dangers, thus sharing country plans and acknowledging the fact that they will not get the vaccine soon is important.

In risk communication campaigns related to HIV, conspiratorial rumors are also common. A lack of access to treatment for vulnerable populations, when other countries have better access, can easily contribute to a narrative that this inequality of access is for a reason. One health communicator interviewed for this research stated that it’s important to confront the uncomfortable realities that may be driving the rumor, “We approached the communication to say, ‘No one could blame anyone for recognizing these inequities, but it’s not a conspiratorial plot, it’s lack of political will’. You need to introduce issues of inequity if you’re going to talk about prioritization. This builds trust, it’s respectful.”

Another contributor added, ‘When communicating the bigger global inequity issues, be transparent and allow people to ask their questions and to vent their rage. We can’t change all the facts of global inequity, but we can listen, empathize and help to release the pressure valve.’”

“The little access to information and technology in hard-to-reach areas draws a fantastic opportunity for self-declared health experts that take advantage of communities’ tensions, confusions and knowledge” - Humanitarian Communicator, Afghanistan

- **Addressing potential scenarios for increased tensions:** Our rumor data from late 2020 suggested that the Venezuelan community in Colombia was initially concerned about their access to the vaccine given the irregular legal condition of many in the country. However, recent news indicates that they will be included in national social security schemes - and vaccination plans- following the announcement of the regularization of over 1 million migrants in the country. Yet, since then, other rumors related to priority access groups have emerged, as host communities increasingly express their disagreement with Venezuelans receiving the vaccine.

A humanitarian practitioner in the Latin American region suggests confronting the reality with them: “Explaining to these groups that they will probably not have access to vaccines any time soon is important, also to discuss the additional consequences and risks that they may face because of that lack of access, including the extreme scenarios that we need to foresee, prepare and communicate about, including increased stigmatization”.

Another humanitarian communicator working in the Western and Central African Region talks about the need to address host communities in advance to boost social cohesion around vaccine access. In this regard, the principles of communication on refugee and migrant health can guide and support these attempts to build public acceptance that no one will be safe unless everyone is vaccinated.

- **Don't tell them it's important and limit their access without explanations:**

The mismatch between the information shared on the severity of COVID-19, and the lack of access to vaccines, could be another driver for misinformation if conversations on priority and access are left unaddressed. Rumors stating that COVID-19 does not exist have been prominent since the beginning of the pandemic. Yet global vaccine-related rumor data collected from across our contexts in the months before and after the vaccine rollout news outbreak in the US and Europe (December and January) suggest that beliefs that COVID-19 is a hoax or corruption plot could also be a widespread response to the lack, scarce or unclear access to vaccines. As some groups are excluded from accessing vaccines that have been promoted as ‘essential for protection’, the trust in those institutions, authorities, or systems may be eroded. Research indicates that social exclusion can drive people towards accepting alternative information and being more likely to find community with groups that may promote conspiracy theories.



FAR FROM HOME:

Where do refugees and migrants fit into vaccine planning?

Throughout history, infectious diseases have been associated with ‘othering’ and in many humanitarian contexts, the challenge of distributing a vaccine has the added complexity of the competing vulnerabilities of citizens, migrants, and refugees - a patchwork of vulnerability that relates to legal status, birthright, and stigma.

The difficulty of working with prioritization, stigma towards these groups, and where the public perceives they should be in the ‘queue’ cannot be ignored. As national vaccination plans are developed and begin to be implemented, the UNHCR is tracking which of these plans include refugees in their national plan and advocating for their inclusion. As of early February, 133 countries were developing national COVID-19 vaccination strategies - 81 had finalized their vaccination plans and 54 of those countries had explicitly included refugees in these plans.⁽¹⁾

In January, Jordan became the first country to provide the COVID-19 vaccination to refugees. UNHCR has been advocating for the equitable inclusion of refugees, internally displaced and stateless populations through the COVAX Facility, a global initiative that brings together governments and manufacturers to ensure that COVID-19 vaccines eventually reach those in greatest need. Low- to middle-income countries have been identified as priority countries for support.

IOM is also working to better understand where migrants fit into distribution planning, but according to our Key Informant Interview, they are ‘working with smoke and promises’ in most cases to determine where national governments will be able to absorb these groups or whether it may fall on COVAX.⁽²⁾

A recent survey to member states found that most countries in Europe are including migrants in national vaccination plans, but the bigger issue surrounds what happens with irregular and undocumented migrants. IOM fears that they will fall through the gap of planning.⁽³⁾ They argue that they do not believe migrants should be prioritized unless they are in conditions where they cannot safely distance (common for migrants who may be more likely to live in overcrowded conditions, shelters, or detention centers). They are not advocating for special treatment - just that migrants are included and prioritized in the same way the local community is prioritized.

In Lebanon - home to the largest refugee population per capita in the world as well as 300,000 migrant workers - refugee groups have not only been included in national vaccination planning but the UNHCR and the United Nations Relief and Works Agency for Palestine Refugees (UNRWA) sit on the national coordinating committee. Refugee and migrant groups will receive the COVID-19 vaccine in tandem with other vulnerable Lebanese citizens. But despite this planning, rumors continue to evolve about when and if refugee and migrant groups will have access.

(1) UNHCR Key Informant Interview, 3 February 2021, (2) Key Informant Interview with IOM, 2 February 2021, (3) Key Informant Interview with IOM, 3 February 2021

One post from Twitter proclaims, “...the United Nations must complete the vaccination delivery for all the Lebanese before giving it to any stranger” while on the other hand, fears swirl within Lebanon about the vaccine being tested on marginalized communities, “They have sent the vaccine to the middle east so they could test it and continue their trials”, one post on Facebook reads.

Whether refugee groups are, or are not, included in national vaccination plans is bound to create a backlash, we have seen this already in data collected in Lebanon and Colombia. These decisions ultimately impact on how we communicate about the vaccine in each context and the impact of that communication on trust relationships. If refugee and migrant groups are prioritized, you run the risk of a backlash from citizens over preferential treatment – if these groups are second in the queue, you risk further stigma and prejudice as they may be viewed as unprotected spreaders of the virus. The ‘us versus them’ mentality is natural when the vaccine is viewed as an article of scarcity and people are desperate for their lives to return to some kind of normal.

Combatting this stigma should be the focus of our communication efforts.⁽⁴⁾ We may need to communicate differently to refugee/migrant groups and with the host population, use different channels and address the key concerns on either side. Encourage host communities to see the vaccination of these groups as part of the global solution to COVID-19 and to not see them as homogenous. Just as in the host community, there are vulnerable groups within refugee/migrant communities that may need prioritization in front of other vulnerable groups.

For refugee and migrant groups, you may also face issues of trust. Many may be unwilling to attend government clinics as part of national campaigns (especially if they have previously been undocumented or unregistered) and humanitarian groups may need to play a role in the distribution of vaccines. In February, the IFRC launched their vaccination program which involves IFRC and national society staff and volunteers engaging with communities on vaccines but also playing a role in vaccination itself in some complex environments where national vaccination efforts may not be able to reach due to remoteness or insecurity.

“ Vaccination comes in stages, that means that at the first the high class and the vaccine will be different for the lower class, in that case, screw it because we the poor people will have the worst as the vaccine will have a different composition ”

- Rumour data collected from a Venezuelan migrant in Colombia

(4) Some examples of guides to address stigma during COVID-19 are [IFRC/WHO](#) and [UNICEF](#), this from [WHO](#) and this from [UNICEF](#).

CASE STUDY:

In Colombia, we witnessed a major policy shift from the Government. In December, in a move that stunned public health experts and prompted condemnation from humanitarian groups, Colombian President Iván Duque had announced, that he would refuse to administer coronavirus vaccines to hundreds of thousands of Venezuelan refugees within its borders. Colombia hosts the largest number of the estimated 5.4 million Venezuelans who have fled economic and political strife in their homeland since 2014. However, in early February, the President, alongside Filippo Grandi, the UN's high commissioner for refugees, announced a new Government Decree that would grant Venezuelan Migrants temporary legal status and access to the potentially life-saving vaccine.

Stigma towards migrant groups has featured consistently as one of the top-ranking themes of rumors surrounding COVID-19 in [our rumor data collected in Nariño, in southern Colombia](#). Rumors highlight fears that the migrants are the source of the outbreak, or that if they are included in national vaccination plans there will not be enough doses for Colombian Citizens. But Migrants are also not immune to rumors surrounding the vaccination campaign. Perspectives collected from migrant communities online and in-person reflect concerns about who will access the different vaccines available, "Vaccination comes in stages, that means that at the first the high class and the vaccine will be different for the lower class, in that case, screw it because we the poor people will have the worst as the vaccine will have a different composition" (Facebook, January 2021).

Rumors, commentaries, and discourses promoting discrimination and stigma are not new in this pandemic. In Colombia, the lack of credible data on migrant infection rates has resulted in the widespread perception that the migrant community is somehow immune to the virus, well before any perspectives on vaccine rollout plans. One of the most violent comments heard in Nariño mentioned that the virus could be cured by "injecting the blood of Venezuelans." In face-to-face conversations and focus group discussions, Venezuelan migrants expressed that these rumors caused them to feel isolated and ostracized, and **decreased the likelihood that they would seek out medical services for fear of being deported or receiving inadequate care due to discrimination.**

Currently, Venezuelan migrants expressed that these new forms of xenophobic commentaries, especially those that **endorse unequal access to the vaccine**, have led the Venezuelan population in Nariño to "hide", to become anonymous, or to avoid social media, making it even harder for them to access relevant credible information. Additionally, the LGBTQI + migrant population has been particularly affected by rumors suggesting that the vaccine will turn citizens into homosexuals. This and the fact that Nariño has become one of the most violent departments for this community, has contributed to isolate this community even further.

WORKING WITH MEDIA:

Frontline information providers

COVID-19 science is evolving – fast – with new findings and insights constantly in the news. This presents challenges to risk communicators, journalists, and their audiences. Guidance and policy decisions may change to reflect the evolving insights from science. When questions arise faster than science can answer them, it is particularly tough for journalists who need to find the language and tone to communicate this to affected communities.

More often than not, each change in guidance is a step forward. Given time, science will correct itself; meanwhile, risk communicators and journalists will need to answer questions where possible and allay fears whilst helping the public develop a mature understanding of the processes in science, inspiring informed debate rather than rush to provide definitive answers to questions when the answers are still elusive. This approach is particularly challenging because of the need for physical distancing during the pandemic. The task of communicating uncertainty in science now falls to more distant community engagement platforms such as complaints and feedback hotlines or the use of social media.

Media outlets that are trusted and serve community needs, in local languages, are an obvious forum through which to communicate both the established science and to address uncertainties and what they mean. They are also a platform for community engagement. Yet local media is often underutilized by humanitarian actors in the pandemic. Given the regularity of global and regional level news briefings (e.g., by the WHO), it may seem unthinkable that media is under-utilized. The reality is that at a grassroots level, where journalists may be less likely to speak the global languages used in these news conferences, journalists are often left wanting.

A key part of the Rooted in Trust project was to support local media to have access to the information they needed to report on the pandemic accurately and responsive to the questions and concerns of their audience. In the 7 countries where we work, more than 800 journalists are members of peer-to-peer networks formed to support each other with information and to connect them with technical experts, training, and resources in local languages. But the key complaint that was common to the members of all these groups was the challenge of being able to access contextually relevant information.

In Lebanon, local journalists told us they struggle to get in contact with experts from WHO and MoPH, apart from pre-prepared materials distributed by RCCE actors. One impact of this is that now many journalists themselves are hesitant to take the vaccine, which also impacts how the rollout will be covered. In the Philippines, national media has been in partnership with the government but there is less support for local media who may broadcast to specific geographies or linguistic groups. In Mali, the government and the MoH mostly communicate in French through national, public media - leaving aside a large part of the population that does not speak French.

In our discussions with journalists, there were two key barriers affecting their COVID-19 reporting:

- **Challenges in accessing information about COVID-19 in local languages** – journalists told us they often relied on the work of other reporters to craft their stories because they could not access source data in local languages. This practice of reporting on reporting not only limits the information available to the journalist and means the information they use may not be appropriate or relevant for their context but presents opportunities for misreporting to be amplified across multiple publications.
- **Challenges in accessing technical experts for interview** – Journalists found that they struggled to find local experts to feature in their stories. Local doctors often struggled to keep up to date with the developments in research about the virus and local WHO offices often struggled to keep up with the demand for interviews or were unwilling to allow local staff the authority to respond.

The latter point, the challenge of the relationship between aid providers and the media, is a touchy issue in health emergencies. Working with local media is often viewed as a ‘risk’ by many agencies. Agencies may have been burnt before if media has been critical of programming or staff which can have both public relations, and at times, protection concerns for staff. This risk is overcome in two main ways, either avoiding them entirely (or diverting requests to spokespeople in head offices) or by constructing a relationship where the aid organization can maintain control of the message.

Let’s address each approach individually.

The first response is to maintain control of the message by limiting who can be the information source. It is understandable why many organizations in this pandemic have been cautious to let their local offices respond freely to media requests. This is a fast-evolving situation - mistakes could be made - and often, local offices may have exceedingly small communications teams. But in a health crisis where accurate information could be the difference between someone accepting a vaccination or not, or choosing to wear a mask for example – why is communication not mainstreamed into our processes? Why are we not devoting more of our attention to ensuring we have staff available, at local, regional, and global levels to share this information?

Granted, not everyone in your organization should be talking to the media all the time without some level of control. But if local journalists cannot access subject matter experts who speak local languages, you risk your carefully constructed talking points being intentionally or unintentionally misinterpreted. If journalists cannot access subject matter experts who understand the local context, you risk accurate, but not contextually appropriate, information being shared that could derail vaccination efforts, for example. And finally, if local journalists cannot access subject matter experts from your organization,⁽¹⁾ they will go elsewhere, and you may lose control of the narrative anyway.

(1) Think for example of the problems that could be caused by media explaining in detail the side effects or benefits vaccines that will not be made available in that country.

The second response often made by organizations is to devise methods to control the message. This can involve paying for airtime – for scripted programming, public service announcements or radio dramas. While important, these messages do not always cover the full spectrum of what people need to know, and often elicit questions in the audience about how the practices can be adopted in real life, for instance where water and masks are in short supply, or where people cannot afford transport to clinics. And while we are not arguing that this kind of programming should never be supported – if we limit our interaction with the media to these approaches, we do nothing to build the capacity of those journalists and content creators over time. We should aim to move beyond messaging to support media to create responsive public service programming without the need for financial pressure from aid providers.

We suggest that local media has three key roles to play in the communication efforts surrounding this pandemic. The first is as a window to community questions, concerns, and perspectives. One of the oldest community engagement tools is talkback radio. And in many remote corners of the world, local media is still the most accessible platform for people to receive information, comment, and discuss. Humanitarian agencies can tap into this resource as another tool to better understand the needs and concerns of their community. In the Rooted in Trust project, we worked with local media partners to build the capacity of local media to be able to document the community perspectives that they are hearing from their audiences and through their reporters. In this way, the feedback from media audiences can be properly logged and analyzed along with streams of feedback being gathered by Internews and other agencies.

This feedback data is also valuable inspiration for local media content. When local media creates this kind of demand-driven feedback loop that directly responds to the questions and concerns of their audience, they are better able to respond to information gaps and identify and respond to rumors as they emerge. A community served by a responsive media that they feel is listening and frankly speaking to them and their concerns is less likely to seek information from less reputable sources.

“Media will be media whether you support them or not. So you can be reported on, or you can report with local media. You need to learn the use of the off-the-record briefing, build the skills of the media. It’s not about having an MOU, or a logo, or editorial approval.”

- Humanitarian communicator, Global

But of course, the questions coming to journalists in this pandemic may be more scientific than the content they are used to working with. Most journalists are generalists – they know a little bit about everything and are being expected to be flexible enough to respond to whatever the daily news cycle throws at them. Very few journalists are health or science specialists. But in this pandemic, there is an expectation that all journalists will be able to absorb, understand and translate complex health and science concepts for their audience. This is information that public health agencies or health-focused aid providers often have, and it is in the interests of both parties that the information should be shared. Very few people would disagree that a better-informed journalist, produces content that, in turn, better informs their audience.

A well-informed journalist is also less likely to misinterpret what has been said in an interview - reducing reputational risk to the organization. Building a trusting relationship over time, providing capacity building on key subject matters, and being open to ‘background’ events or discussions will ultimately contribute to building the skill level of local media so that when they do conduct an interview, they are able to ask better questions and act as a more efficient information provider.

The third reason is often more controversial. While humanitarian agencies agree that being open and transparent to our communities about how we conduct our business and make decisions is key for building trust and being accountable for our actions, few organizations are open to local media questioning their activities and interactions. But this is a key function of a healthy media. It would be hypocritical for an organization to promote free speech, accountability of elected officials and the media as the Fourth Estate, and then shy away from also being held accountable in this forum. Yes, there is risk associated with this kind of interaction, but there is also the immense benefit of contributing to building trust with our communities and being openly responsive to their needs and preferences. Why is it that many agencies see the benefit of answering these questions in a community or town-hall meeting event, but not in local media, where they have the opportunity to reach a far larger audience?

Some of this reluctance speaks to the issue raised earlier of not having enough (or any) people in local offices trained or ‘cleared’ to communicate about programming publicly. One contributor to this research explains that media will continue to publish, whether you help them or not: “Media will be media whether you support them or not. So, you can be reported on, or you can report with local media. You need to learn the use of the off-the-record briefing, build the skills of the media. It’s not about having an MOU, or a logo, or editorial approval. Partnership building, these are all the things that the NGO fundraising group understands, or the head office communications teams understand, but at the field level the approach needs to change.”

BETWEEN A ROCK AND A HARD PLACE:

How do agencies balance Government relationships and public information needs

Employing diplomatic and advocacy strategies to persuade decision-makers to act in the best interest of humanity is key to humanitarian interventions addressing structural and chronic challenges and inequalities. In the COVID-19 vaccine roll-out, humanitarian agencies play a unique role in both collectively and unilaterally advocating for communities and maintaining humanitarian principles of neutrality and impartiality – something that can be challenging within a government-led pandemic response. Diplomatic advocacy looks different for each humanitarian agency depending on their approach to activism and advocacy, and each approach presents challenges and opportunities.

Navigating advocacy is critical in instances where governments are complicit in misinformation, disinformation, or in some cases refusal to be transparent and informative about the COVID-19 vaccine rollout. As detailed above, lack of communication about vaccine access and uncertainty can have a significant impact on effective uptake of the vaccine, and consequently on the physical and psychosocial safety of people. So, what do humanitarian organizations do in locations where the governments are not communicating or are sharing false information?

In our Rooted in Trust focal countries, we witnessed governments not publicizing infection rates, promoting unproven treatment and prevention methods, and accepting vaccines from foreign powers that were yet to be proven effective by the wider scientific community. The experiences of a range of humanitarian staff interviewed for this paper indicate dilemmas of complying with government plans and directives in situations where those directives are at odds with WHO recommendations and block

addressing tough questions or rumors related to the vaccine. Critically, this stalemate of communication decreases trust in humanitarian information and feedback loops.

Government action preventing sharing of information has been evident during the COVID-19 pandemic response in certain countries (for example, through internet shut-downs, slowing of freedom of information compliance, restrictions on media reporting and restrictions of movement) and this continues to be a serious risk.

In Afghanistan, the Government has issued a direction that only official and approved messages about the vaccine may be shared with the community. This is not only causing delays in communication, but Humanitarian actors argue, may in fact cause protection concerns for field workers, and the community, when organizations are prevented from listening and responding to the questions they receive from their community. Some organizations have said that they will not communicate about the vaccine at all if they are restricted to government-produced key messages.

If national/local experts, accountability mechanisms, and advocacy groups are silenced or restricted, this impairs transparent and equitable vaccine roll-out. Humanitarian agencies play a key role in both providing experts and accountability mechanisms directly, as well as resourcing local/national organizations working to combat these restrictions.

Risk Communication and Community Engagement (RCCE) groups in the country are key channels for coordination of advocacy efforts, using community-level feedback data to advocate for contextualized messaging at the local level. With this approach, some key informants noted RCCEs can play a role in enabling environments where local civil society organizations, community health workers, religious and community leaders, and local media can act based on what is locally relevant, rather than what is mandated by governments. In Afghanistan, key informants spoke of improvements in government participation and trust in RCCE mechanisms, potentially a step towards a more productive space for vaccine communication. National RCCE groups need strong links to COVID-19 vaccine taskforces and national response plans, need to be bolstered by regional and global RCCE structures, and reinforced by strong accountability mechanisms within member organizations.

In the face of international vaccine trade tensions and lack of transparency in funding and procurement efforts, global level advocacy and activism is occurring from a growing movement of health and humanitarian organizations, health experts, faith leaders and economists. These groups are repeatedly raising concerns that governments are not acting in ways that ensure vaccines are available for the “global public good”. Since the COVID-19 pandemic began, hundreds of temporary trade measures have been enacted by governments, aiming to restrict exports and liberalize imports of vital medical supplies and other essential products such as personal protective equipment. As governments continue to prioritize their own citizens in this way, lack of diplomacy and coordination is resulting in a hindered global capacity to target supplies based on need, a continued risk for vaccine equity.

Among others, the People’s Vaccine Alliance is urging for the rate and scale of vaccine production of vaccines to meet the needs of all people in all countries, free of charge. They are calling for the prevention of monopolies on vaccines through the removal of intellectual property and patenting, transparency of price and accessibility, distribution at the country level based on total population – including to marginalized groups like refugees, prisoners, and people living in slums. The Alliance also publicly notes criticism against the COVAX initiative’s lack of transparency and inclusion and advocates for decision-making fora to include civil society and governments in developing countries.



RECOMMENDATIONS

- **Replace the narrative, not the fact:** Responding to rumors with facts is not enough, you need to tell another story. Respond to actual questions and concerns and respect the dignity of the person and give them the agency by giving them more complex information in accessible formats.
- **Trust your community:** Your community deserves to access enough information to make informed decisions. Understanding the information needs of the community must start with listening. Agency builds ownership. Build systems to regularly listen and engage and to involve the community and their preferences in the design of vaccination communication activities and the vaccine rollout.
- **Don't be afraid to say, 'I don't know':** We need to be transparent and clear about what we do, and don't know about the vaccine and the rollout and be ready to answer questions. No one has all the answers on the pandemic and pretending we do is setting ourselves up for failure. Admitting our own information gaps can help to build realistic expectations from the community, break down barriers and allow for community-led solutions in the absence of national or global directions.
- **Listen and analyze community perspectives continually:** No community is homogenous or static. If misinformation or hesitancy is evident, look to see if there is a particular group that believes this message more than others. Work to understand if it is a majority view, or the views of a vocal minority.
- **Communicate vaccine risk:** informed decision-making requires people to understand the benefits and the risks of any action. All vaccines have risks. Communication activities can explain these risks in relation to the individual and community benefit the vaccine also presents.
- **Re-think your Messengers:** think about who is a trusted health source locally, and who they are trusted by. Trusted sources of health information may differ from the sources people go to for other kinds of information. Trust may have a strong association with proximity. Build long-lasting relationships with trusted information providers to establish further community trust, provide continuity of communication (even if the message may need to be flexible) and a reliable space to continue to have their questions and concerns addressed.

- **Discuss motivation:** What motivation is there to be vaccinated? People do not have to get vaccinated, understand what might motivate them to seek vaccination, and speak to that motivation. The motivation might be personal (travel, job opportunities, health), family (protecting vulnerable loved ones), or even at the community level (the lifting of wider COVID-19 restrictions, etc).

- **Narrowcast:** Initial rollouts are likely available to specific vulnerable groups (Elderly, co-morbidity, etc), look at how you can reach these groups on the platforms they prefer with specific information about uptake (where, when, how) and focus broader communication efforts on expectation management of when/how the rest of the population might be able to access the vaccine. This narrowcast method is also useful to address specific groups in the community that might have particular concerns or hesitancy or speak minority languages.

- **Stages of engagement:** Plan for different stages of community engagement at each point of the vaccine process. People will have different information needs, different anxieties, or experiences impacting their behaviors and practices. The first phase of engagement should start well before the vaccination begins to explain the process and allow ample time for questions. Communicate openly throughout the vaccination process and the final stage of communication will run well after vaccination is complete (potentially 1-2 years) so you can fully cover the shift to the ‘new normal’.

- **Don't wait for a national rollout campaign:** Citizens are more connected than ever before, if you're not talking about vaccines and answering questions, they will look to debates overseas that may not be relevant and may confuse the information ecosystem.

- **There is a problem with joined-upness:** Communication and engagement considerations should begin in the initial planning of any system. They need to be designed in tandem to prevent communication from becoming an underfunded afterthought. Communications and RCCE teams need to work more closely together and collaborate, they should all have the same aim of getting high-quality information to the community.

- **Design communication products with the community:** Work with the community to not only understand how they prefer to receive information, but also to design communication products that meet their needs. Products designed alongside the community are less likely to feel like directives, will feel local, contextualized, and familiar. Design communication systems that allow you to be responsive, rather than “messaging”. The long delays caused by multiple levels of approvals needed for “messaging” can mean the information becomes stale and over polished; it loses its local relevance or quality or the recognition of the original questions.

- **Acknowledge and empathize with fears and concerns:** Fear is a legitimate response to uncertainty. Acknowledge that people may be feeling anxious and rather than focusing on data and complex language, talk like a real person to make a connection and build trust.

- **The vaccine is not THE solution:** Avoid talking about the vaccine as ‘the solution’ but rather that is ‘part of the solution’. Pair any vaccine discussion with information to manage expectations that preventative measures are here to stay, at least in the short-medium term.

- **Let the community lead the conversation:** Having communities explain to one another why conspiracy theories or rumors are wrong is a core approach of the HIV movement. Invite people to talk openly and honestly about their concerns and to share verified information with each other. Treatment literacy is peer-provided empowering people with knowledge about the disease, how to ask questions, how to take medicine, how to talk to your doctor etc.

- **Encourage a community-minded perspective:** A lot of the messaging tends to focus on individuals or nodes – protect yourself and your family. In a crisis, people tend to focus on individualism. Encourage people to think wider than that to see it more from a community sense, ‘this is something you do to protect your whole community and reduce the impact on all your lives’.