



Inequity Driven Mistrust

Its Impacts to Infodemic Management and Health Response and what to do about it



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Introduction.

The COVID-19 pandemic, along with other recent health crises, has highlighted the detrimental impact of misinformation and mistrust of health information on health systems. Studies have underscored the negative associations between mistrust and various aspects associated to a health response, including health outcomes, utilization of preventive health services, willingness to receive care (including vaccination), mortality rates during an emergency, perceptions of risks, and overall acceptance of health measures ([Lee & Lin 2011](#), [Musa et al. 2009](#), [Ahorsu 2021](#), [Reiersen et al. 2022](#), [Bollyky 2022](#), [Pian et al. 2021](#)). Understanding what drives mistrust in health information and what possible actions can mitigate or address the impact that this mistrust has on the effectiveness of health emergency response is critical ([Mulukom 2022](#)). Given the significant role that trust plays during a health response, it becomes paramount to take a deeper look at what the main drivers of trust in health information are during a health crisis. This research is situated as part of the [Rooted in Trust \(RiT\)](#) project at Internews, which since 2020 has partnered with over 41 local organizations in 15 different humanitarian settings to respond to the unprecedented scale and speed of health-related rumors and misinformation. As part of our project, we have identified that inequity is an important driver of mistrust, particularly for at-risk communities in humanitarian settings. Inequity has also proven to be an important social determinant of health that can have an impact on health outcomes ([WHO, 2008](#)).

A recount of the existing literature shows a significant gap, which this paper aims to begin to address. Some studies have conceptualized information inequality as the lack of access to factual and scientific information and emphasized how it contributes to the rise of misinformation ([Mostagir & Siderius, 2022](#)). However, “infodemic”¹ management has shown that access to scientific evidence alone does not necessarily curb the spread of health [misinformation](#) ([Internews, 2020](#)). Consequently, other studies have increasingly focused on structural inequalities and their role as social determinants of health to understand their influence on inequity-driven mistrust and misinformation. These studies have emphasized how societal issues such as structural racism, vulnerability, and discrimination influence marginalized communities’ mistrust of health-related information with impacts on health outcomes ([Musa et al., 2009](#); [Jaiswal et al., 2020](#); [Bazargan et al 2021](#), [Rasheeta 2020](#), [Da Silva Et al 2021](#), [Smith 2021](#)).

However, many of these studies have primarily focused on at-risk communities in high-income settings, particularly in the United States. As a result, there is a literature gap when it comes to understanding how inequity-driven mistrust operates for at-risk communities in low-income settings, specifically in humanitarian contexts. Factors such as unreliable health care systems, widespread poverty and inequality, geopolitical conflicts, post-colonial tensions, and weak institutions may alter the ways in which inequity-driven mistrust operates in those contexts.

¹According to the WHO the infodemic is too much information including false and misleading information in digital and physical environments during a disease outbreak.

Furthermore, existing studies have primarily examined how inequity-driven mistrust influences health behavior, without adequately addressing its impact on “infodemic” management, health emergency response, or humanitarian response.

This paper aims to address these gaps by investigating the ways in which inequity can contribute to mistrust in information

among at-risk communities in humanitarian contexts. The goal is to shed light on the potential impacts of this mistrust on health emergency response and “infodemic” management. To achieve this, the paper provides an empirical account through case studies conducted with internally displaced communities in northern Iraq and indigenous communities in the Colombian and Brazilian Amazon regions.

The research is guided by three main objectives:

01.

To understand how inequity can drive mistrust in health information among the participating communities **(Section 1).**

02.

To categorize the ways in which this inequity-driven mistrust can impact “infodemic” management and health emergency response **(Section 2).**

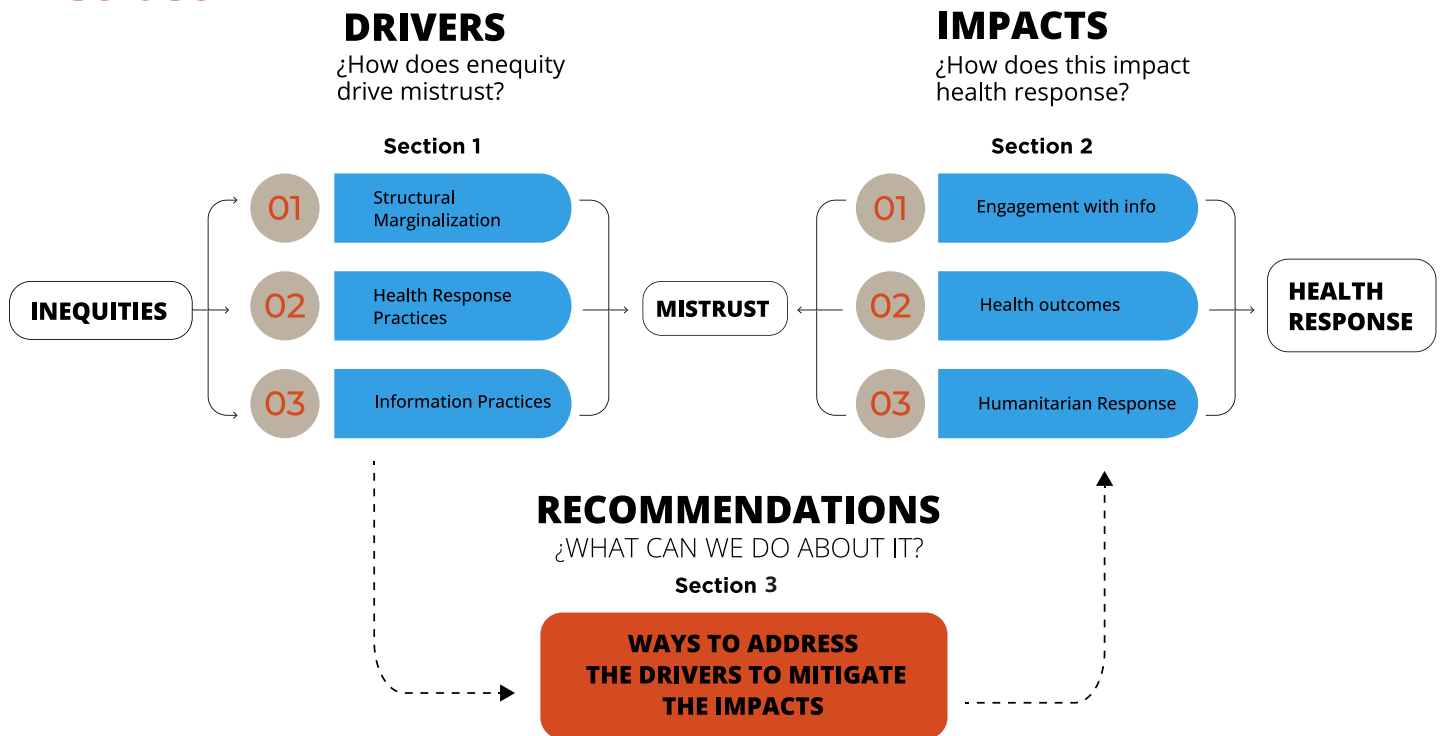
03.

To identify strategies for mitigating, addressing, and acknowledging the impacts of inequity-driven mistrust **(Section 3).**

Our findings have identified three main drivers through which inequity can drive mistrust in information: **(1)** structural inequities and grievances; **(2)** inequities during the health response; and **(3)** inequities directly associated with the information response. These three drivers demonstrate that at-risk populations in the low-income settings can experience inequalities at the national, regional, and global levels, which are often entrenched in postcolonial structures of knowledge production, unequal health systems, and/or disproportionate medical supply distribution. Furthermore, we

have identified three major possible impacts resulting from inequity-driven mistrust: **(1)** impacts on the way communities engage or disengage with official information; **(2)** direct or indirect impacts on health outcomes and communities’ relationship with health systems; and **(3)** impacts on communities’ engagement and relationship with humanitarian responses. Finally, we provide a set of recommendations for possible ways in which various stakeholders that are a part of the response can address the drivers of inequity-driven mistrust to mitigate the impacts.

Inequity Driven Mistrust



Overall, the research argues that inequity is an important driver of mistrust in health information for at-risk communities and that a failure to acknowledge and mitigate the effects of deep-rooted inequities can seriously hinder the efficacy of “infodemic” management efforts and health emergency response.

Analytical Framework.

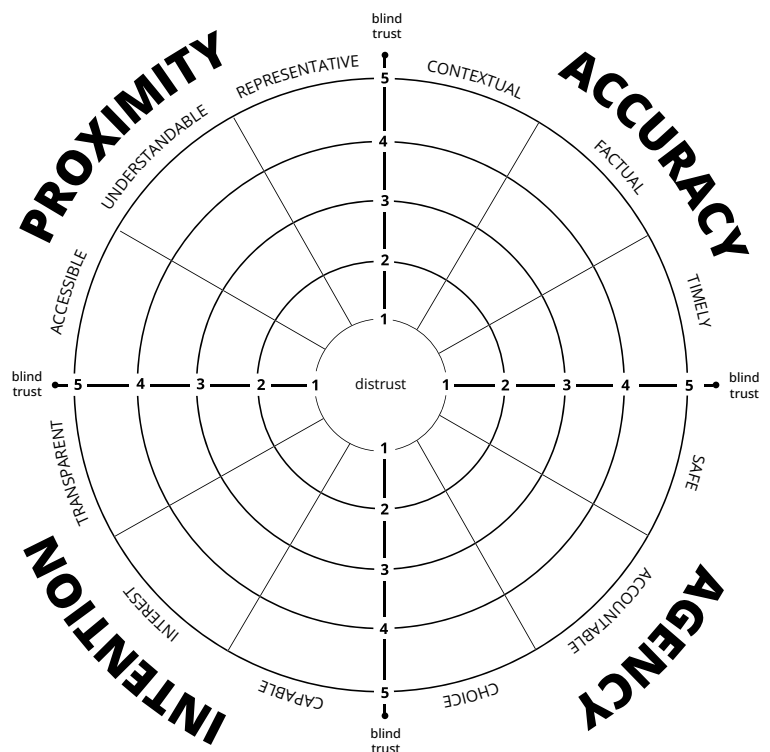
The concept of inequity is central to this research. While inequity and inequality are related concepts, they have distinct meanings that were carefully considered. Inequality refers to the uneven distribution of resources, opportunities, or outcomes within a society, such as income, wealth, education, or social disparities. In contrast, inequity goes beyond inequality and emphasizes the fairness or justice of such disparities. It focuses on perceived unfairness, injustice, or avoidable disparities, considering factors like social justice, fairness, and human rights.

For this study, we did not focus on studied, quantified, or previously identified inequities but rather employed a bottom-up methodology to allow participants to define what they perceived to be the main inequities faced by their community during and before the COVID-19 pandemic. We arrived at a common understanding with participants that an inequity could represent any perception of injustice, unfairness, or inequality commonly associated with an unbalanced power dynamic with a single or group of actors and with economic, social, epistemological, or cultural implications. We also explained that the perpetrators of the perceived inequities could be abstract (structures, systems, or forces in society) as well as institutional (public, private, or non-governmental) at local, national, regional, or global levels.

Once the perceived inequities were identified, our focus was not on statistically significant, realistic, or factual assessments of these inequities. Instead, our aim was to explore the emotions associated with those inequities and their impact on trust in information.

Trust is another central concept in the analysis of this research. Throughout the paper, we make direct reference to [Internews' trust framework](#).

The trust framework is a conceptual and practical tool used to understand the core elements that drive trust in information. The framework consists of four core elements: **(1) proximity, (2) accuracy, (3) intention, and (4) agency**. Each core element also has three sub-elements, which provide a more in-depth understanding of how the framework operates. The framework is meant to be used as a tool for the evaluation of trust in communities as well as a guide to improving trust relations. The framework shows that trust is a dynamic process that exists in a spectrum influenced by the 4 core elements and the 12 sub-elements. Throughout the paper, primarily in chapters 1 and 3, we refer to elements and categories of the trust framework. We encourage readers to look at and utilize the framework for more context on what we mean by the different elements.



Methods and Limitations.

This research was conducted by Rooted in Trust (RiT) teams in Colombia, Iraq, and Brazil. Each country had a specific at-risk population of interest and a region where the study was conducted. In Colombia and Brazil, the focus was on indigenous populations in the Amazonian region, particularly in the isolated Amazonian department of Vaupéz. For the case study in Iraq, the focus was on IDP camps in the northern Kurdistan region of the country. The majority of the IDP camp population where the study took place had some association with the recent (2013-2017) conflict with the Islamic State (IS). The methodological steps consisted of:

1. Inequity Maps

We began by creating word maps of inequity in Brazil, Colombia, and Iraq. The goal was to identify frequently used words in rumors related to inequity. We requested word lists from RiT national teams, encompassing institutions, regions, public figures, and expressions associated with inequity in their respective contexts.

2. Rumor Analysis

Utilizing the word lists, we extracted and analyzed subsets of rumors from the RiT database that contained those words. This process allowed us to identify common themes and classify the rumors based on their scope, mentioned actors, and the Internews trust framework ([link to rumor maps](#)).

3. Data Collection

Based on the identified themes, we developed research instruments to be implemented in Colombia and Iraq. We conducted four focus group discussions (FGDs) in Colombia and Iraq and held 16 stakeholder KIIs in each context. FGDs were conducted with diverse groups of community members who had been beneficiaries of RiT programming. The KIIs included discussions with media, humanitarians, civil society, community healthcare workers, and community leaders.

4. Data Analysis

We employed a combination of deductive and inductive qualitative coding to identify themes related to the avenues through which inequity drives trust in information, the impacts of inequity-driven mistrust, and possible recommendations to mitigate those impacts. For privacy purposes, we refer to the key informants by the sector they represent rather than the specific organization they were speaking for.

Our research primarily focused on exploring inequity-driven mistrust and its impact. While positive examples of local collaboration were considered for the recommendation section, they were not extensively elaborated on in the findings section. This limitation may have resulted in a somewhat one-sided description

of dynamics, highlighting the need for more comprehensive research that better understands contextual complexities.

Additionally, our study was constrained by a limited number of key informant interviews (16) conducted across two contexts. Conducting additional research in diverse humanitarian locations would be valuable to broaden perspectives. Given the complexity of each context and community, our understanding of historical, social, and political dynamics is limited. The paper does not suggest that all at-risk commu-

nities face the impacts or drivers of inequity-driven mistrust in the same way. To explore other layers of results, further research is necessary to examine these dynamics. Furthermore, language and translation challenges, particularly in the Vaupes context, should be considered when interpreting the findings and conducting future research. To address these limitations, future studies should pursue a more multi-faceted approach, expanding the scope of analysis and enhancing understanding of contextual dynamics.



Section 1

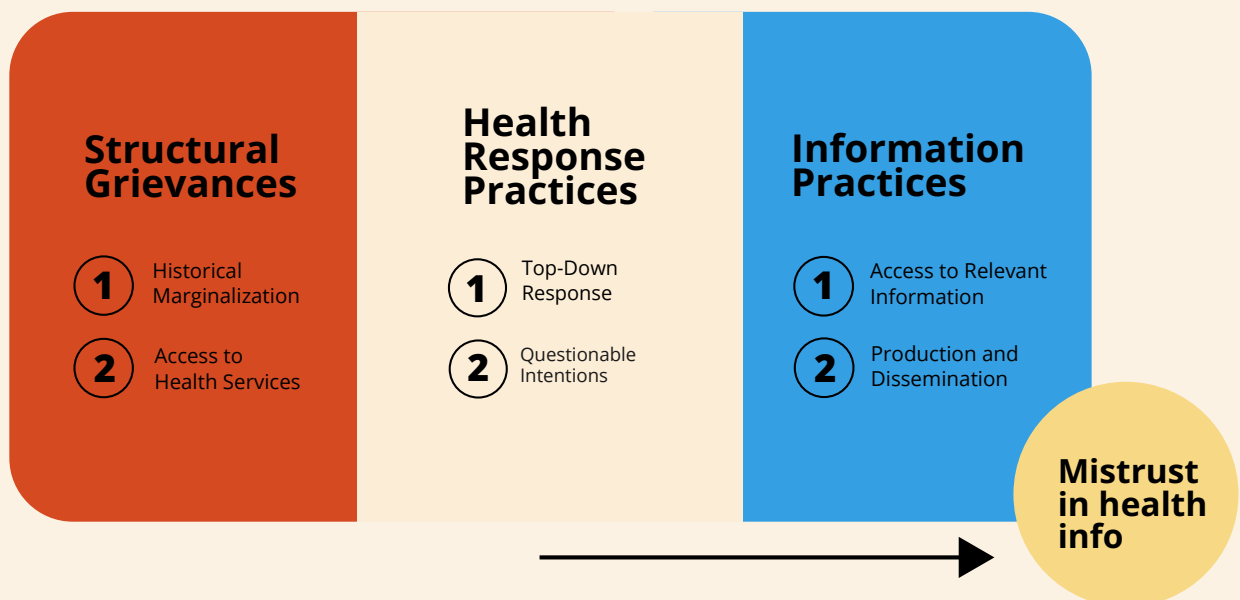
Drivers through which inequity influences trust

This section explores the drivers through which inequity can influence mistrust in health-related information. The objective was to identify historical and ongoing grievances amongst the participant communities and understand how these interplay with the trust or mistrust they have in health-related information, with a particular but not exclusive focus on the COVID-19 pandemic. Interviewees were asked about the main inequities or injustices that communities

experienced during the pandemic. Once these were identified, the questions aimed to determine how these factors influenced their trust in health-related information.

We identified three major, non-mutually exclusive, drivers through which perceived inequities influenced trust in health-related information.

Drivers ¿How can inequity drive mistrust?



The first driver refers to those structural inequities that communities experience that are not directly associated with the provision of information or the health emergency response but that end up having an impact on the trust that communities have towards actors or institutions and, as such, on the health-related information that is communicated by them. This first driver consists of two subcategories, which include: (1) historical processes of global and national abuse and marginalization associated with conflict, geopolitics, and post-colonial structures; and (2) inequalities directly associated with limited access to quality health services and resources.

The second driver refers to perceived inequities during and as a part of the health emergency response that end up impacting trust in health-related information. This second driver consists of two subcategories: (1) a top-down response characterized by limited or tokenistic community participation, a lack of willingness to listen to communities' feedback, and a limited presence of response actors in communities; and (2) instances of corruption in the response often associated with empty promises and unfair enforcement of health measures.

The third driver refers to perceived inequities associated directly with the provision of health-related information during a health emergency. This third driver consists of two subcategories: (1) limited access to relevant information, which includes information that is factual and transparent, localized, actionable, in the preferred language, and that promotes dialogue; (2) inequities in the production and dissemination of information, which include a lack of representation in the production of

information and a disjointed nexus between information and service provision.

The three drivers demonstrate the complex, longitudinal, and fragile nature of trust. During a health crisis, the mechanisms through which inequity influences trust in information are dynamic and the result of practices and structures before, during, and as a part of the health emergency response. Inequities present as part of the information response can be influential on trust in information. However, practices and inequities present in other areas of the response (such as service provision) and in society as a whole (in the distribution of resources) can also be influential on the trust communities place in information. Additionally, in developing or humanitarian settings, at-risk communities may experience inequalities at the national, regional, and global levels. These inequalities can be cemented in postcolonial structures of knowledge production, unequal health systems, and/or disproportionate medical supply distribution, and can end up influencing their trust in information. While these communities experience inequities within their national contexts, we also identified instances in the collected rumor data of generalized feelings that their country also experience inequities in a global system.

Despite the identified complexity, it is paramount to understand the ways in which inequity-driven mistrust operates, as well as its impacts on information management and health response (Section 2), in order to identify ways to mitigate and address those impacts (Section 3). The remainder of this section provides detailed descriptions of each driver identified, along with examples from rumor data and interviews.



* Driver 1

Structural inequities

This first driver is about historical and ongoing marginalization that exist before and persist during the health emergency response without being directly a part of the response. Those structural processes are demonstrative of the temporal element of trust as something that is built and lost over time. Furthermore, as argued previously by Internews, trust is also something that, once lost, becomes hard to rebuild ([Internews, 2020](#)). In addition to existing literature, this study also finds that for vulnerable populations in the low-income settings, the structural inequities that drive mistrust in information are also exacerbated and characterized by regional and global geopolitics and post-colonial relations. In these contexts, on top of the mistrust generated by national actors (governments, private sector, civil society, etc.) there is also a feeling of inequity experienced by their country in a global context. Overall, this section reinforces the argument that trust in information extends beyond the communication strategies that form part of a response as it is also the result of historical and ongoing inequities that permeate different societies.

Below, we present two of the categories identified under structural inequities. The first is about historical marginalization and the second one is about direct mentions to access and quality to health services. The two categorized are very much interconnected and reinforce each other, however it is useful to differentiate for analytical purposes.

■ Historical marginalization

In our data, we identified numerous examples of historically fractured relationships between communities and actors at the local, national, regional, and global levels. These relationships often resulted in the mistrust of information provided during health crisis. In many instances, the fractured relationships were caused by the actions or inaction of these actors. The inequities resulted in perceived poverty, a lack of stability, a loss of freedom, inequality, a lack of mobility, discrimination, and marginalization, all which fuel inequity-driven mistrust.

The following quote from an interview with a local media organization in Iraq shows the ways in which intertwined power relations between actors at different levels can influence trust in information:

““

“Of course, Iran is interfering in Iraqi issues and the West is as well... People are very skeptical of everyone because there's not much improvement in the infrastructure... It's always easy for other actors to interfere and influence people ... There are local actors who are actually campaigning for regional actors, so it's very difficult. And the foreign interference is very clear.”

Local Media, Northern Iraq

At the global level, the rumor data demonstrated many tensions with global governance institutions, pharmaceutical industries, and philanthropic public figures. These feelings were often due to perceived interference in the sovereignty and freedom of choice of developing nations, which were cemented by post-colonial feelings of dependence and submission to a global and northern system. This type of tension is particularly detrimental to the agency element of the trust framework, which posits that the freedom and sovereignty involved in making informed decisions is a key element of trust in information. The below example of a recurrent social media rumor identified in Brazil highlights these tensions:

“

“The goal of WHO is to subordinate all countries to it, thus seriously injuring the sovereignty of nations. This means again lockdowns, unemployment, breaking the economy, and the loss of rights guaranteed by the Constitution... Brazil is sovereign! We do not accept being submissive to foreign entities... Fight today if you don't want to be a slave tomorrow!”

Brazil Social Media Rumor

At the national and local level, we identified tensions with government, military, and civil society institutions, many of which were motivated by feelings of abandonment, abuse, and corruption. This made it increasingly difficult for communities to trust the intentions behind health-related information that was associated with those actors during the pandemic. For example, the following interview with a community leader from Iraq demonstrates some of these tensions:

“

“We cannot trust the central government because many people in this camp here are survivors from ISI. So, for example, they were told to return to their houses and the government took them in and locked them in prison for 15 years. So even if they provide {health information} to us, we cannot trust it ... If the government has not even provided legal help for us, how can we trust the other information they bring?”

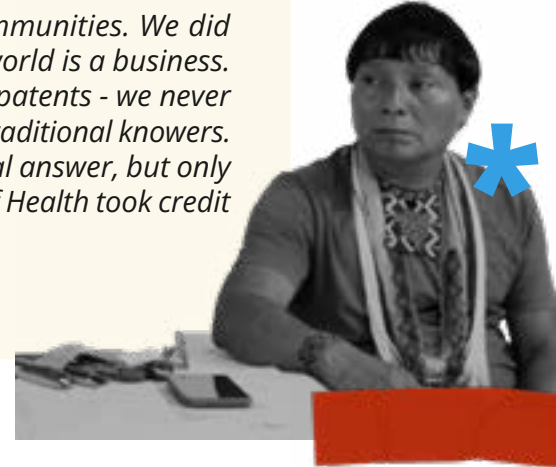
Community Leader IDP Camp, Northern Iraq

Furthermore, we also identified historical tensions between local knowledge systems and what is perceived as western science. In some cases, the concerns over the perceived lack of historical collaboration between their ways of knowing and the knowledge that they perceived as coming from ‘the west’. This was particularly the case for established and ancestral ways of knowing, such as those of indigenous communities in Brazil and Colombia. Many of these complaints are rooted in historical and post-colonial abuse that has attempted to destroy, extract, and commercialize indigenous knowledge, particularly in areas related to health ([Brown Et Al 2012](#), [Simpson 2004](#)). In the southeastern region of Colombia, in the department of Vaupés, indigenous communities expressed their frustration with the ways in which certain health institutions demanded cures and solutions for the pandemic derived from indigenous knowledge without a real attempt to create intercultural collaboration and exchange. For example, a community leader explained how something as simple as the western diet that indigenous communities are forced to eat when hospitalized is already a huge barrier to true collaboration between ways of knowing. The following excerpt from a focus group discussion with indigenous communities in Vaupes is representative of those tensions:

“

“There was an exchange of knowledge, but only among our own communities. We did meet inside the maloca² to see how to take care of ourselves [...] The world is a business. We never handed over our ways of preparation - just like the Western patents - we never shared our wisdom with others [...] There was no coordination with the traditional knowers. They would have hired the Payés³ to have both a Western and ancestral answer, but only what they [the doctors] said was what had to be done [...] The Ministry of Health took credit for the work of the sabedores⁴ .”

Focus Group with Indigenous Leader, Southern Colombia



In comparison, we also captured examples of how [Sinergias](#), a civil society organization and partner in the Rooted in Trust (RiT) project, effectively navigated an honest and two-way dialogue between indigenous knowledge systems and western science throughout their response. They even had a well-respected traditional healer as collaborator and technical advisor, this greatly contributed to the trust that this organization has been able to establish with the communities it serves.

There is another side to this historical unequal tension that we identified across the three countries. These are instances in which science, just for the fact of being perceived as ‘western’, is seen by communities in the global south

as superior or more factual. There are many factors that have influenced this construct, one of which has to do with the historical inequality that has permeated scientific knowledge production, making it increasingly hard for global south scholars to participate in global debates ([Posada & Chen, 2018](#)). In our data, we identified multiple rumors and disinformation that mention a western country or a western university to increase the credibility of the information they are sharing.

For example, when we told a health actor in Iraq about the tensions that we had identified in Colombia, this was their reaction:



“

“Here in this country, have a totally different perspective. We don’t trust the locals. They trust those who studied in Oxford and all of these places and in the US. We hear things such as this scientist in the US said this and that. We need to believe in him.”

Humanitarian Agency, Northern Iraq

²A maloca is an ancestral long house and community meeting place used by indigenous people of the Amazon, notably in Colombia and Brazil.
³Payes are traditional healers in the Vaupes region of Colombia. They are also referred to as the “knowers” and serve as a bridge between the spiritual and natural world.
⁴Sabedores translates directly to “the knowers” which is a way to refer to the traditional healers and elders.

■ Access to Health Services

This second category is directly related to inequalities in the access and quality of health services both before and during a health crisis. These factors ultimately impact the trust that communities place in health-related information. Vulnerable communities in the low-income settings are particularly susceptible to facing challenges in accessing healthcare. However, as demonstrated in this section, these challenges are not uniform across all communities. This will be further explored in section 3, which focuses on recommendations and emphasizes the importance of tailoring responses to the specific needs of these communities.

Distrust in hospitals and health services was a common characteristic of COVID-19 misinformation worldwide. One of the drivers behind mistrust in health care is the unequal distribution and the actual quality of services available to a community. In Southern Colombia and Northern Iraq, we identified complaints about the quality of care received by vulnerable communities in hospitals.

The interviews revealed that a history of low-quality health services and workers influenced the trust that communities placed in information encouraging them to seek medical care. Interviewees mentioned health personnel with limited training, inadequate infrastructure, and insufficient equipment and supplies as contributing factors. For instance, an interviewee from Colombia mentioned that in Vaupés, three ICU units were provided, but nobody knew how to operate them effectively. The connection between low-quality health services and the reluctance to trust information promoting the use of those services may seem obvious, but it is often overlooked and not acknowledged in attempts to address health service-related misinformation. In line with the trust framework, low-quality services raise doubts within communities about the capability of actors to care for them, even if these actors have the

right intentions. This, in turn, influences the level of trust placed in them.

The following excerpt from an interview with a humanitarian actor in Iraq presents this relationship:

“

“There are very poor health systems. People would go to do something in the hospital, minor surgery, and they would die in the middle of the process. So all of these things created this gap and a lack of trust between the people and their government.”

Humanitarian Agency, Northern Iraq

Alongside the quality of health services, another major issue that was identified was the ability of communities to access them. It becomes complicated for communities to trust information that asks them to seek health services when none of the barriers and challenges that are hindering their access to them are being addressed. While both the Iraq and Colombia case studies talked about difficulties in access, the reasons for those difficulties were quite different. This exemplifies the importance of acknowledging the contextual reasons behind a trust issue that might seem similar, but that can have very different drivers.

In the context of the Vaupes region in Colombia, indigenous communities have always had trouble accessing health services because of their geographical isolation. Many communities must travel multiple days by boat to get to the nearest hospital. Outreach health teams visit the closest villages to the provincial capital of Mitu on a regular basis, but for those located

deep into the rainforest, access to health care is almost non-existent.

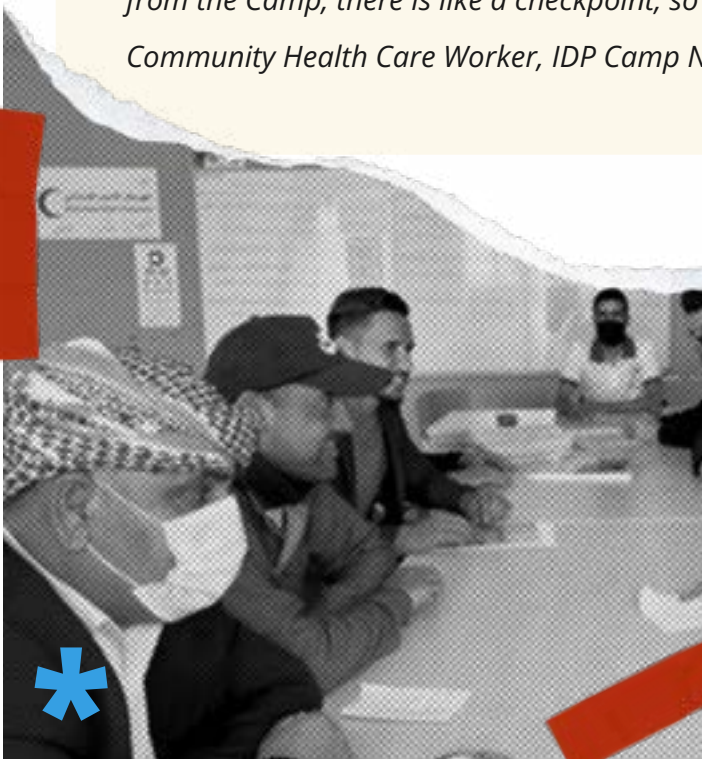
Furthermore, patients with severe cases of disease normally need to be flown by plane to another city with higher-quality hospitals. In the pandemic, the limited medical equipment available at the Mitu hospital exacerbated the need to fly critically ill patients to cities such as Bogota and Villavicencio. According to our interviewees, most of those cases ended up dying alone in a foreign city without the ability to bring the body back. This created a lot of mistrust in Mitu hospital and in any information associated with it. Because of this, indigenous communities often chose to remain within their villages when getting sick and engage in ances-

tral medicine practices to cure COVID-19. The IDPs in the rural communities of northern Iraq also shared with us experiencing a lot of issues accessing health services. However, the reasons were very different. In theory, IDPs are close to quality hospitals, but in part because of their association with the Islamic State, their mobility is restricted, and they face many difficulties leaving the camp, let alone visiting a hospital. They are often unable to travel to Erbil or Mosul, where they could access to specialist treatments. This generates a lot of frustration inside the camp, which is also manifested as mistrust in the health response. This point comes across in the following excerpt of an interview with a health care worker in the camp:

“

“I tell them {Central Government}: What do you want to do? Do you want to kill all the IDPs in this community? Because if you want to kill them, okay, keep them {without mobility} and kill them. But we need to treat people. We need to serve people, but this is not service. Because it's not just prescribing painkillers, sometimes people need specialized appointments, they need high-level intervention, they need surgeries. And currently they cannot get it... And we cannot do these things inside the camp because there's no {operating} theater. If they go to Mosul from the Camp, there is like a checkpoint, so they are stuck.”

Community Health Care Worker, IDP Camp Northern Iraq



The history of inequity-driven mistrust because of structural inequalities makes communities concerned and suspicious of the intentions behind the information provided during a health emergency response.



* Driver 2

Inequity during health response

This section focuses on the inequities that exist within the health emergency response, separate from the information response, and that impact trust in information. These inequities pertain to perceived disparities during the design, implementation, and evaluation of a health emergency response, involving various actors beyond just the national health system. While the first section demonstrated that there are structural factors influencing trust in informa-

tion, this section argues that there are factors within the health response that are not directly related to the information or communication aspect but still affect trust in information.

The section is divided into two interrelated characteristics of an emergency response that, based on our data, contribute to inequity-driven mistrust.

Top-down response: limited participation, unwillingness to listen, and lack of presence

This characteristic relates to the top-down approach in designing and implementing a health response. A top-down response can negatively impact trust in information by undermining the perceived accountability of response actors and creating doubts about their intentions. Our data consistently revealed frustration with top-down responses as a recurring theme.

First we identified frustration over the nonparticipation or tokenistic participation of communities in the health response, not just as beneficiaries but also as decision-makers and implementers ([Arnstein, 1969](#)). The lack of participation affects the community's trust in multiple regards. On one side, it contributes to mistrust in the intentions of those involved in the response as it limits those actors' ability to address communities' real needs and limits transparency and accountability. On the other hand, when communities sense that others are

profiting/benefiting from the implementation of the response and they are not, it increases mistrust in the interests of the implementing actors.

For example, we identified frustration by communities in the ways in which they are involved in the design and implementation of the response. The importance of involving local leadership that can represent the interests of the communities at the time of designing a health response becomes essential because it contributes to a contextualized response that is rooted in communities needs and concerns ([Kamuzora et al 2013](#); [Schoch-Spana et al 2007](#); [Larson et al 2009](#)). A civil society interviewee from Colombia highlighted the detrimental effect of failing to work with local indigenous councils in the design and implementation of the health response. There was also a lot of frustration from community actors about the

perceived lack of involvement of traditional healers (in that region referred to as *sabedores* or the ‘ones who have the knowledge’). The interviewee explained that this was worsened by the fact that the elected Governor during the pandemic did not understand the local

dynamics. By not understanding and involving local structures, the response might not be adapted to the local context and strengthens the notion that decisions are made far away, by people who are not part of the community or even have taken into account their perspectives.

“

“The new one who assumed that new governorship he did not have clear knowledge of the indigenous organizational structures. Because he is not from here ... If you don't work with indigenous people and you are not involved in all these dynamics, you don't have the context in your mind. This happens with people who come from institutions from the interior of the country, as they don't know these organizational structures and the dynamics of the department, they do and plan without considering that here there is an own government {amongst indigenous communities}. And they must be included in everything. Because in the end, they are the ones who have an impact and understand the whole territory”.

- Civil Society Organization, Southern Colombia

While non-participation can have detrimental effects on trust levels, not all forms of participation are necessarily trust-inducing. There are tokenistic participations in which community members are involved or encouraged to contribute ideas without real power or decision-making influence. This type of participation can also affect trust in health response actors and, as such, in the information that they provide. This is also true when community

leaders are used as vessels to transmit information in locally appealing manners, but they have no influence on editorial decisions, and how the information provided might relate to actual community needs and expectations. The following excerpt, where a humanitarian actor in Iraq reflects on things she has heard on the field, demonstrates the frustration associated with tokenistic participation:

“

“I've heard a lot {from communities that}: you guys come to take pictures to give to donors and then just ditch us in the middle of the process and leave. So, you don't do it for the humanitarian issue. But you do it more for the donor thing. You just do whatever you want to do on the field and use us as a tool to get the money and then just leave. ”

- Humanitarian Agency, Northern Iraq

There is also frustration associated with the lack of participation of non-traditional health actors, such as media and civil society, from the design and implementation of the health response. We identified frustrations with the limited role that civil society organizations and local media were given at the beginning of the health response. This was particularly true in Colombia, where our interviewees expressed

frustration with the centralized approach that health secretaries had at the beginning of the pandemic, failing to include those actors that had closer relationships with communities and that could have played a more significant role in the response. Those same actors expressed how their eventual inclusion as part of the response positively affected health actors proximity and relationship with indigenous communities.

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“The initial mechanism was very centralized in the departmental health secretariat, and it was there where that all the guidelines of those who should be involved in the response teams in the territory in relation to the COVID issue were handled. So we wanted, logically, not to feel useless but to be able to contribute. So it was also a first challenge because, from the institutional framework, we saw that we were not taken into account at the beginning as an actor to be able to generate some actions outside of information or interact with some leaders”

- CSO Leader, Southern Colombia

Another practice that contributes to a top-down response is the unwillingness to genuinely listen to communities, particularly when they express criticism of the response. This lack of two-way dialogue fosters mistrust and leads to an implementation that fails to address the specific needs of communities. We identified frustration stemming from a lack of willingness to receive feedback. Local and community media in Colombia shared accounts of facing backlash due to the open and two-way dialogue their radio station maintained with

indigenous communities. They explained that the radio station operated with an open mic policy, allowing community members to voice their opinions and express their needs. In many instances, community members voiced criticism and concerns regarding those implementing the response, which sometimes included elements of misinformation. As a result, the station faced backlash from authorities and was occasionally accused of being responsible for spreading misinformation and disinformation.

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“The radio station is also open to the community; people can call on the air to ask questions and say what is going on. This is why the authorities sometimes get annoyed with the radio station because people make demands through the radio station.”

- Local Radio, Southern Colombia



Finally, we also identified the impact which a constant and long-standing physical presence in the community has on building trust. As explained by a civil society interviewee in Colombia, **“they {communities} trust the entities that accompany the people {on the ground}”**. She was referring specifically to the church and religious leaders and why communities had so much trust in them during the pandemic. We identified a similar case in Iraq where a community leader explained that **“people here mostly trust the camp manager.”**

This is because they {camp management} go on tours, they visit people, gather with them in specific areas, and talk to them about how to protect themselves.”

However, just as presence can drive mistrust, a lack of presence can also drive mistrust. This is what we identified in Colombia when a local leader explained that **“The territorial entities did not even appear, the mayor’s office and the governor’s office were no longer trusted because they did not show up at any time. So, they didn’t trust them.”**

■ Questionable Intentions

This second characteristic has to do with corruption or unethical practices by those involved in the response, which end up driving mistrust as communities question the ability, intentions, and transparency of those involved. Here we identified cases of empty promises, unequal enforcement of measures, and an untimely response.

We identified multiple instances in which communities were promised things as part of the response that were not actually delivered. This had huge effects on the level of trust in the response and its actors, which indirectly affects the trust that communities have in the information provided. As mentioned in the trust

framework by Internews, transparency around the ability to deliver is one of the variables that affects trust in information. We recognized that empty promises can be the result of multiple factors. On one side, there is the danger of overpromising, without necessarily having ill intentions. On the other side, there are mal-intentioned promises with the objective of getting buy-in but with no actual intention of delivering. This second one can be used as a strategy to generate instant short-term acceptance, but in the long term the effects on trust can be monumental. Many times, the failure of some to deliver can also have an impact on trust in the entire sector. This was explained by a humanitarian actor that we talked to in Iraq:

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“Many NGOs are making false promises to communities. They say things like: Fill out this survey for me, and I’ll make sure to help you, bring food and diapers and milk to your kids, and then they just leave. This builds this lack of trust between the community and different agencies and NGOs. They come, take whatever they want, and just leave and never come back. So this all affects even our interventions when it comes to Risk Communication and Community Engagement (RCCE)⁵, which is all about building trust. If you don’t build trust in your community, I cannot convince them of anything. When I go to them there is this destroyed relationship between me and them even before I see them. And it actually affects a lot of our health interventions, and it gives us a very hard time trying to do our best for them.”

- Humanitarian Agency, Northern Iraq

⁵According to the international rescue committee RCCE aims to mitigate the risk and impact of an outbreak by offering an approach and set of tools to work with communities to prevent exposure, stop disease transmission, and mitigate the harmful effects of the outbreak.



There are also complaints about corrupt or unequal enforcement of health response measures. During the pandemic, this was mostly seen in cases where people had to actually follow stay-at-home orders. For example, a social media rumor captured in Colombia, shows the frustration faced by indigenous and afro-Colombian populations given the severe

consequences that stay-at-home orders had on them given the informality of their employment. This coincides with multiple studies that explain the ways in which stay at home orders have disproportionate effects on lower income populations ([Basu et al 2021](#); [Partha & Kalam 2020](#); [Cho 2021](#)).

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“As Afro and indigenous communities we don't like being locked up, the authorities said that we had to be locked up and they gave us a fine, but we had to work. The majority believed that they were government pretexts, they said that everything was an invention of China to reduce to the population.”

Social Media Rumor, Colombia



* Driver 3

Inequity as part of the Information Response

This final driver addresses the unequal practices that directly contribute to the information response during a health emergency, leading to a sense of mistrust in the information provided. Here, we identify inequities related to access to relevant health information and the processes involved in producing and disseminating that information. This third driver emphasizes the importance of the proximity and accuracy

elements within the trust framework. While accuracy is typically associated with access to factual information, the timeliness and relevance of the information within the given context are equally significant. Proximity is influenced by the accessibility, representativeness, and understandability of the information for the targeted community.

■ Access to relevant information

Lack of access to adequate information tends to be the most critical injustice that is associated with inequity-driven mistrust. While access is significant in shaping trust, our data demonstrates that it is not just about the availability of scientific or factual information, but that it has

a lot to do with the relevance of what is available. Below we highlight some of the elements of information that when missing decrease the relevance of the information available and as such affect the trust that communities have on that information.

Factual

Access to verified, verifiable and factual information is an important driver of trust in information. In Iraq, we identified instances in which a weakened information ecosystem limited

the availability of verified information. On top of driving mistrust this also created the space for discriminatory narratives against vulnerable communities to emerge

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“In the Iraqi information ecosystem, the media is actually very unhealthy. We don't produce a lot of quality objective journalism. People don't receive verified information. So it is very difficult for people to actually decide what they want. This actually leaves the room for waves of hate speech because ...the Iraq information ecosystem is full of hate speech and hatred against minorities and IDPS”

Local Media, Northern Iraq Trust framework: Factual

Localized

Even when factual and verified information is available, communities want that information to be localized in way that speaks to their real needs, contexts, and realities. Vulnerable communities are often exposed to information that is produced for general consumption,

but that does not speak to their reality. When information is available, but it fails to respond to the specific needs and concerns of its audience, it creates the perfect space for the rise of mistrust and the proliferation of rumors and misinformation.

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“So, of course, when there was so much information about what was happening outside {in the capital and other countries} and the anguish of so many dead people, so much, and yet there was no clarity about what was happening here. Well, I believe that this disinformation generated a lot of anguish among the people. I think there was no one telling them what was going on in their context”.

- Civil Society Organization, Southern Colombia Trust framework: Contextual

Prescriptive

The imposition of information, as opposed to a dialogue, is also a driver of inequity-driven mistrust communities want to have the capacity to take their own informed decisions.

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“They did not ask us if we accepted or did not accept to vaccinate us. We only heard that you must do it. After that, I found out that there are some decrees that say that we can decide if he wants to be vaccinated or not.”

- Community Leader, Southern Colombia Trust Framework: Choice



Language

The lack of access to information in local languages can lead to a sense of distance and mistrust between the community and response actors, as language is a crucial element of proximity. By delegating content creation to local

partners who can create content in the local language and incorporate local expressions, the resulting information is more likely to be trusted and understood by the community, thus reducing inequity-driven mistrust.

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“People do not trust - nor did they trust during the pandemic -in hospitals. Indigenous people have historically been rejected in the health system. There are no referrals for us, there is no translator either. People don't understand what they're saying.”

Listening group rumor, Colombia Trust framework: Understandable

Actionable

There is also frustration when information doesn't offer practical solutions. When people don't receive information that helps them address the specific risks and challenges they face, mistrust can arise. Many vulnerable communities experienced this during the

COVID-19 pandemic, where much of the information and recommendations provided were tailored towards urban populations with greater resources, making it irrelevant or difficult to apply in their own contexts.

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“Community's expectations were anchored to their needs and gaps, so they had the idea that local authorities would provide medicines and give clear parameters to combat the virus, instead of scientific information and recommendations that they perceived as complex and far from the reality of the territory, such as “wash your hands with soap every now and then”, when access to these inputs has always been complicated”.

Focus Group Report, Colombia Rooted in Trust Team Trust Framework: Contextual

Sources – Transparency

Finally, a lack of transparency around the sources and motivations behind information can also drive inequity-driven mistrust. Communities' trust in information providers is influenced by a range of structural grievances and practices that exist during the health response. Therefore, it

is important not only for communities to have access to information, but also to know who is providing it and what their intentions are. The involvement of actors with whom communities have had strained relationships can impact how that information is received.

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“Do your homework: pause the video, write down the names, and check for yourself each of these cases. If you are waiting for the Brazilian popular media (TV, newspapers, magazines, news sites, etc ...) you can forget. Let's say it is not good for business to disclose news raising questions about @reacoesadversas suspected of being linked to covid vaccine. The more stupid and ignorant a people, the easier it becomes a faithful consumer clientele. Your heart ❤️ Thanks!”

Social Media Rumor, Brazil

Production and dissemination of information

This section is about inequities related to the way in which information is produced and disseminated. Our data suggest that, along with access to relevant information, the “how” of information production is also an important driver of trust. During the process of producing information, we identified relevant inequities in relation to the lack of community involvement in the production of information, as well as extractive practices in the ways in which information was collected.

Communities expressed frustration with the lack of involvement that they had in the production of the information that was shared. Lack of representation ignites a feeling of inequity, which also contributes to mistrust and a lack of relevance in the information provided. For example, a local media outlet in Iraq explained, **“Basically, the Iraqi underprivileged groups, such as minorities and then IDPs, refugees, women, victims, and so forth, are not well represented in the media. They don’t have a space in the media, and there isn’t enough reporting in terms of quality and quantity about those groups.”** He explained how those vulnerable groups have constantly expressed frustration with the lack of involvement: **“They**

have always been shouting and saying that we don’t have enough representatives in the newsroom. Our voices are not being heard.” He also continues to highlight some of the negative impacts associated with the lack of representation of communities in the production of information: **“When communities are not well represented, this brings about a lot of waves of hate speech against them; they don’t have any tools to protect themselves... So we end up without the other side of the story.”**

A lack of transparency in data collection practices can also contribute to mistrust in the information that is presented. Ethical and transparent research practices are an essential component of building trust. In both of our main case studies, we identified frustration with extractivist practices in the collection of data. They referred to cases in which actors came with questions to collect data but failed to provide useful information or services in return. Extractivist research can also have many post-colonial implications for knowledge extraction, which, as explained in the first driver, can trigger historical and structural elements of inequity-driven mistrust ([Igwe et al 2022](#); [Tembo Et al 2021](#)).

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“There is an NGO ... which also operates in certain territories and that has generated a lot of distrust because ... they say that they have come and investigated, but they do not know where the investigations are or where the information is ... so they say that they take the information, they steal it, they take it abroad, and that they have made books from it.”

- Civil Society Organization, Southern Colombia

During the dissemination of information, we also identified frustration over poor coordination between service and information provision, which contributed to feelings of untimely and irrelevant information responses, affecting trust in information. This was a recurrent theme, consisting of instances in which information had been provided without the supply of services, or vice versa cases in which services had arrived without any accompanying information. This

highlights the importance of having an information response that is properly articulated with the provision of health services.

For example, in Colombia, a local leader explained how visits from health professionals who only came to raise awareness but did not provide any services generated mistrust among the community.

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“They just came with words, words, words, words, and went back. Meanwhile the indigenous communities were waiting for something that would be useful for them. Not for them to just arrive, say hello, talk about it, and go back. “

- Community Leader, Southern Colombia

An opposite scenario but with a similar outcome was also recorded in an interview with a vaccination leader in Colombia. Here, she explained how some vaccines were distributed to certain territories without any prior information, which resulted in mistrust and low vaccination uptake.

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“We did not manage to make a previous sensitization, but, I mean, it was also the issue here of the vaccines because of the weather and that, the vaccines had to arrive here, as we did not have the freezers; they had to leave; they almost arrived at once”.

- Vaccination Leader, Southern Colombia



Section 2

The impacts of inequity-driven mistrust

This second section is about the detrimental impacts that inequity-driven mistrust can have on information management and health emergency response. The objective is to demonstrate that inequity is a significant variable to consider

for those concerned with the ways in which trust in information impacts the effectiveness of health emergency responses. Through our analysis, we identified three main potential impacts resulting from inequity-driven mistrust.

Impacts

¿How does inequity driven mistrust impact health response?



The first impact relates to the ways in which communities engage with information due to mistrust driven by inequity. We have identified two opposing practices that have similar negative impacts on the health of an information ecosystem. On one hand, there is active engagement in spreading rumors and disinformation fueled by grievances and frustrations arising from mistrust caused by inequity. On the other hand, there is disengagement from formal information interventions and an active search for alternative sources resulting from frustration and mistrust associated with the inequities experienced before and during the health response. When people feel that information does not accurately represent their reality or address their needs, they can disengage from information providers, even if those providers offer factually correct information, and instead seek information elsewhere. This disengagement poses severe threats to the health of the information ecosystem, particularly during times of crisis, as people may turn to alternative sources that are potentially less reliable. Therefore, both active engagement and disengagement from the official information response present severe threats to the health of the information ecosystem.

The second impact is in relation to the direct and indirect effects of inequity-driven mistrust on communities' health systems and health outcomes. Regarding the direct effects, we identified an unwillingness to follow health recommendations partly because of the frustra-

tions associated with inequity-driven mistrust. This was exacerbated when the recommendations were transmitted by those actors that communities held responsible for the inequities they faced during the pandemic. The unwillingness to follow recommendations also included COVID-19 vaccine hesitancy. In terms of the indirect effects on health, we identified a vicious cycle in which inequity drives mistrust, which can further exacerbate the inequities. One of the results of that cycle is the increased distance and isolation it imposes between communities and health systems.

The third impact is in relation to the ways in which inequity-driven mistrust influences the relationship between communities and humanitarian or civil society organizations. Here, we identified that inequity also increases the frustration that at-risk communities feel towards the actors that are meant to represent their needs and serve them. This increases the distance between humanitarian and civil society organizations and results in an unwillingness to participate in their programs or activities.

The three impacts demonstrate the significant detrimental influence that perceptions of inequity can have. Not only does it jeopardize the health of an information ecosystem, but it also contributes to deteriorating relationships between communities and all actors in positions of power. This, of course, has an impact on the possibility of having an effective information and health emergency response.



* Impact 1

Engagement with Information

Through our data, we identified that inequity-driven mistrust had an impact on the ways that communities engage with information. While for some it results in active and frustrated engagement with rumors and disinformation, for others it results in a decision to disengage and withdraw from official institutional information providers and search for alternative - in some cases lower quality - sources. Both seem-

ingly opposing practices can emanate from a similar frustration and have detrimental effects on the health of the information ecosystem.

The remainder of this section presents a detailed analysis with examples of the ways in which engagement and disengagement were presented in the data.

Active Engagement with Rumors and Disinformation

We identified that one of the possible reactions emanating from frustrations associated with inequity-driven mistrust is the decision to actively engage with misinformation (unintentionally false or inaccurate information). What we identified is that grievances associated with inequity created a lot of doubts and questions (many times legitimate) amongst communities, which could reach the point of turning into a rumor. For example, a community health care worker in Iraq explained, **“It [inequity] affects us because communities do not trust us from the very beginning. When we go to help, they have this trust issue. They ask themselves: Are they real? Are they here to serve us? Is it for real, or do they just want to give us the vaccination? Which is sometimes turned into ‘they will make us infertile’. Because they reach a point where they do not trust anyone because everyone has tried to abuse them in different ways”**. A humanitarian actor in Iraq also explained how rumors associated with inequity-driven mistrust spread when the vaccine was administered to IDPs: **“In the camp the rumors started going around that the government doesn’t care about us, and suddenly they want to vaccinate us. Yeah right, they’re bringing us expired things”**. In Colombia, we saw a similar situation in which

a government decision to vaccinate indigenous communities first was met with backlash when the communities’ rumors that they were the first to get vaccinated because the state wanted to experiment with them just as they had done in the past.

We also found that inequity-driven mistrust can be used to give traction to disinformation (the purposeful spread of fake news) campaigns. What we saw is that by acknowledging and incorporating the historical and ongoing marginalization that communities face as a result of inequity, disinformation campaigns can gain a lot of traction. While the information might be fake or incorrect, the emotions that it is addressing are very real and important in the imaginaries of the communities that it is targeting. The following excerpt from the team’s report of the focus groups in Colombia provided an example of this point: **“Some disinformation campaigns have fed on this inequity-driven mistrust, combining several of the aforementioned rumor trends to undermine the importance of vaccines, claiming, for example, that : the miracle solution—vaccine—is a poison and many people have serious health problems. It’s a lucrative business, a double-edged sword for the pharmaceutical industry”**.

As such, the information ecosystem is greatly affected by the ways in which inequity-driven mistrust gives rise and traction to misinformation and disinformation. As part of the Rooted in Trust project, we have been collecting health-related rumors circulating among at-risk communities in humanitarian contexts for the past two years. In preparation for this paper, we collaboratively and systematically analyzed all of the rumors collected from Iraq, Colombia, and Brazil. The objective was to identify the ways in which perceived inequity is represented in our rumor data. The result was a set of rumor maps per country with a thematic analysis ([Link to rumor maps](#)). Overall, some of the major themes identified consist of:

01. Rumor Trend: Perceived injustices by powerful actors

This set of rumors speaks of perceived or suspected injustices carried out by actors at the national and global level. The most recurrent set of actors included: politicians, pharmaceuticals, philanthropists, media organizations, and global institutions.

a. Censorship: There were multiple instances of rumors that expressed frustration over the supposed censorship experienced by those critical of the vaccines or the health response at large. A key component of the trust framework is accountability which posits that information providers should encourage their audiences to ask questions, scrutinize and amend information with their perspectives and insights.

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“How honorable doctors are silenced from telling the truth... I spoke with several doctors in the West Bank...during the campaign of poisonous doses, and they confirmed that when they tried to discuss this issue and the extent of its morality, they were threatened with revocation of their license and harm.”

- Social Media Rumor, Iraq

b. Transparency: Lack of transparency was also a common perceived injustice that we identified in our rumor data. We identified many claims that governments and pharmaceutical industries had purposefully left out information or data about the side effects of the vaccination. On previous publications we have written about the importance of communicating vaccine uncertainty ([Internews 2021](#)).

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“Pfizer and the CDC were hiding data that showed damage and death from the vaccine. What’s happening here is criminal. For people who knew the data but didn’t say anything, there will be legal consequences... They will either be witnesses or defendants.”

- Social Media Rumor, Brazil

c. Data Privacy: There were also numerous instances of rumors that expressed frustration of the lack of data privacy and safety by powerful actors. Collecting data has never been easier which has also increased concerns over the risks associated with the proliferation of biomedical surveillance as a result of the COVID-19 pandemic.

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“UN digital ID will have access to all significant aspects of your life. They will connect the citizen to a global network that will define their social credit score, ability to work, travel, buy or sell, enroll their children at school, receive health care, register or access a place to live and so on; All managed by the same benevolent people who now sponsor the new narrative of “Stay home ... if you can.” With all aspects of our digitally centralized lives using biometrics, facial recognition, blockchain, artificial intelligence and an extensive 5G network, have you ever wondered what kind of social control this could provide if people decide not to obey certain restrictions or requirements”?

- Social Media Rumor, Brazil

d. Corruption: We also registered many frustrations over supposed economic or political benefits by powerful actors at the global and national level resulting from health measures associated with the pandemic. From our rumor data we identified how the supposed corruption made audiences question the intentions and capacity of information providers.

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“NEW WORLD ORDER: The next pandemic is going to be more lethal, says Bill Gates, and everything is already set up to make it happen. With NGOs, with the Bill and Melinda Gates foundation, and a bank, to take care of all the financial stuff, to immunize people.”

- Social Media Rumor, Brazil

02.

Rumor Trend: Tensions between global and national agendas

This set of rumors speaks about geopolitical tensions between global institutions or global north countries and countries in the global south that resulted in feelings of injustice or inequity.

a. Loss of sovereignty: A recurrent theme across our rumor data was a feeling of loss of freedom and sovereignty by nation states in the hands of a global governance structure and under the excuse of global health agenda. This supposed foreign or global interference appears to create a lot of mistrust and worries amongst those behind the rumors. In countries with a history of colonialism or foreign interference there is a particular historical grievance associated with the loss of national self-determination.

“

“WHILE PEOPLE ARE DISTRACTED BY SOAP OPERAS, BEER AND SOCCER THE 2030 AGENDA OF THE WORLD ECONOMIC FORUM MOVES FORWARD. Pandemic: the perfect excuse to make all countries give up their sovereignty and decision-making power and deliver them into the hands of an international body. Compulsory vaccination, vaccination with the use of police force, health passport requirements to be able to hold a job, shop at the supermarket, or keep your children in school - what if all this were no longer decided by us, through the political power of each state, but by foreigners, international bodies that know better than the citizens themselves what is best for their health?”

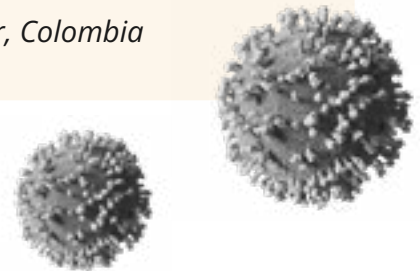
- Social Media Rumor, Brazil

b. Historical grievances: Historical conflicts and tensions between western countries and those in the global south also contributed to rumor data associated to inequity-driven mistrust. This was particularly true for countries that had been at war, colonized, or invaded by western countries. For example, in the case of Iraq and other middle eastern countries where we work, we have identified multiple rumor trends with anti-western sentiments which mention the western invasion of the middle east. Similarly, in South American countries we have also captured rumors that reference the colonial past.

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“The elders were mad: they said things like White people always bring us diseases, this is not the first time.”

- Social Media Rumor, Colombia



c. Western science and knowledge systems:

This set of rumors spoke about tensions between knowledge systems and science. It included claims of a predominant “western” science and the labeling of critiques as enemies of science. It is rooted in the unequal history of knowledge production which makes it harder for other knowledge systems to have legitimacy or participate in global debates.



“They are in control of everything, from your job to your religion to politics, whether left or right, they control your food, your medicine to false science. (You imply that Antony Fauci, as well as Bill Gates, are Illuminati).”

- Social Media Rumor, Brazil



Rumor Trend: Health service inequities

This set of rumors speaks about health system inequalities faced by communities or countries.

a. Access to quality health services: This are rumors related to the access to low quality health services which end influencing the trust that communities have in institutions and as such in the information or recommendations that those institutions provide. This also included tensions about an unequal distribution to health services, including vaccination, which end up affecting at risk communities disproportionately.



“The second issue is that vaccines are not the same in the whole world in terms of quality, the vaccine sent to Baghdad is much better than the vaccine in the region. With all kinds of me, I have distanced myself and my family from this talented vaccine - Pfizer is much better because Europe used than the Chinese one”

- Social Media Rumor, Iraq

b. Measures exacerbate inequity:

These rumors included claims that the pandemic and the response measures ended up further exacerbating inequities for at risk populations. This includes things such as stay at home orders and isolation orders.



“Poverty increases the harm caused by diseases such as corona and cholera on individuals. ----- One of the causes of the disease is the return of displaced people to their places of residence because their environment is contaminated with toxic gases”

- Social Media Rumor, Iraq

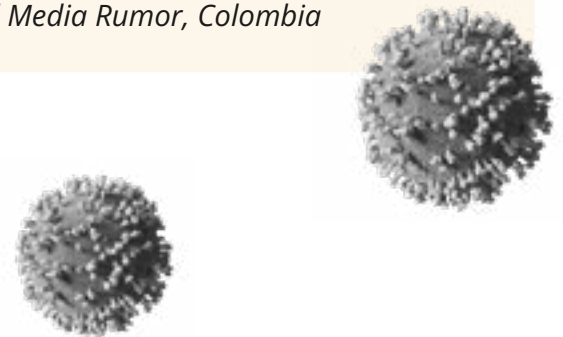
c. Discriminatory services:

This set of rumors spoke about discriminatory access to health services particularly for at risk communities. It included complaints by indigenous, IDP, or LGBTQI populations at the time of accessing health services during the pandemic. It was also comprised of various expression of frustration and injustice in the access to health services by those that decided not to get vaccinated.



“Until when? We don't have to be afraid to use medical services just because we haven't injected ourselves with the experimental vaccine. Where is your humanity? I ask the doctors...”

- Social Media Rumor, Colombia



Disengagement from the institutional response

Another possible consequence of inequity-driven mistrust is the decision by communities to disengage from information from official institutional actors and an active search for alternative sources. This poses a significant challenge for the official health response, as it limits its capacity to provide lifesaving and essential information to communities during a health emergency. This might end up being a harder challenge than the active engagement described above. With those that are engaging, there is at least the possibility to foment dialogue and reach agreements. However, when official information loses importance and relevance, it becomes much harder to navigate the impacts.

The following religious leader from Iraq explains some of the processes that drive the disengagement from institutional sources: **“If they’re not receiving the assistance on time, for example, the food supplies, that’s every three months, they completely don’t trust the health. This is the real struggle. So they don’t care about health information because they’re not receiving essential assistance on time”.**

This was also emphasized by a community leader when he was asked how the IDP community would react to information received from the central government, which we had previously identified as being responsible for many of the inequities that they face.

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“Even if they provide us information, we cannot trust them because we’ve been here for a long time and they have not taken action. And if they brought information, we would still be afraid of them. We would think that maybe they will not provide us with the proper information.”

- Community Leader, Northern Iraq

The disconnect between official information providers and communities can also contribute to the search for alternative sources, some of which may be of lower quality and potentially harmful, as will be discussed further in the following section.

* Impact 2

Health Outcomes

Inequity-driven mistrust can also have a direct or indirect impact on health systems and health outcomes. Directly it can lead to an unwillingness by communities to follow health recommendations during a health emergency as well as actively seeking alternative treatments and

preventive measures, some of which can be life threatening. Indirectly, the frustrations resulting from inequity-driven mistrust can increase the distance and further disrupt the relationship with health actors. This results in a vicious cycle in which inequity-driven mistrust further

distances communities from health actors which in turn exacerbates the health inequities that these communities already face. The remainder

of this section provides examples and a more detailed account of how those direct and indirect impacts on health outcomes operate.

Unwillingness to follow health recommendations

The frustrations associated with inequity-driven mistrust can contribute to an unwillingness to follow health recommendations during a crisis. If people mistrust the information, there is less incentive to pay attention or follow what is being proposed by that information. In instances where the mistrust is very severe, the effects of the recommendations can even backfire, resulting in community members taking the

completely opposite action or seeking alternatives. This impact is inherently related to the rise of misinformation and disinformation presented in the previous section. Rumors also contribute to an unwillingness to follow health recommendations during a health emergency. This transcript from a focus group in Colombia explains how rumor tendencies associated with inequity-driven mistrust contribute to a delegitimization of the virus and the vaccines:

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“These rumor trends have influenced the perception of the virus’s illegitimacy, present in some collective imaginaries where the general public doubts the existence of the virus, its potential severity, the importance or relevance of vaccines, biosecurity measures, and other actions taken by the government and transnational organizations to address the health emergency.”

- Focus Group Report, Southern Colombia

This was also exemplified in an interview with a youth leader from Colombia who was asked about how the youth reacted to information that was brought by actors that they did not trust due to inequity-driven mistrust:

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“Well, they received the information from those actors, but they never followed it. They would say things like that the information is not useful, it is not true, why would we follow it or believe it.”

- Youth Leader, Southern Colombia

The inequity associated with a lack of information and services can also push communities to seek alternative solutions in terms of cures and preventative measures for the virus. Some of the alternatives can be quite dangerous and pose a greater health risk; such as the numerous cases of rumors that suggested the unsupervised use

of chloroquine to treat COVID-19⁶. In the case of Colombia, the focus groups evidenced how, in the face of inequality in relation to access to medical services, indigenous knowledge in many instances became the only viable alternative.

⁶ The FDA has cautioned against the use of chloroquine for COVID-19 outside of a hospital setting or a clinical trial due to risk of heart rhythm problems.

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“During the pandemic, the community experienced an escalation of pre-existing barriers due to the excessive bureaucracy of health institutions. This bureaucracy caused delays in hiring medical professionals and allocating resources for the purchase of biosecurity supplies. It is at this point that the aforementioned element emerges: ancestral medicine. Ancestral medicine not only serves as a means of preserving and utilizing the community’s traditional knowledge to enhance their physical and spiritual well-being but also acts as one of the limited approaches to addressing diseases, considering the scarcity of professionals and resources in Western medicine that could potentially complement these efforts.”

- Focus Group Report, Southern Colombia

Exacerbates inequities and isolates communities

Not only does inequity-driven mistrust influence communities’ willingness to follow health-related recommendations, but it also erodes the relationship between those communities and healthcare providers. This can lead to long-term and irreversible damage as trust is broken. Issues such as unfulfilled promises and unequal access to services contribute to this widespread frustration with healthcare actors. For instance, during a focus group discussion in

Iraq, it was observed that many participants no longer trusted the services provided by health clinics. According to the participants, this lack of trust was partially because the government and organizations made repeated visits and promises without taking concrete actions. An interviewee from a humanitarian health agency also highlighted how the strained and distant relationship between communities and healthcare systems impacted their work.

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“During the pandemic, we witnessed a significant amount of hesitancy among people and a lack of trust in both people and governments. Unfortunately, this hesitancy stemmed from various factors, including sectarianism, inadequate healthcare services, a challenging political situation, instability, Islamic State presence, the refugee crisis, and informal settlements for internally displaced persons (IDPs). These circumstances were extremely challenging and posed a burden on our work. There was a notable sense of hesitancy between communities and the healthcare systems, leaving us stuck in the middle.”

- Humanitarian Agency, Northern Iraq

The ruptured relationship between communities and health systems contributes to a vicious cycle which further exacerbates the inequities faced by communities. By distancing themselves from health systems communities are less likely to be able to position their health needs

and concerns in the policy of service provision agenda. As a result, there is an increased likelihood that those needs will not be considered or addressed, which further increases the inequities that damaged the relationship in the first place.

* Impact 3

Humanitarian Response

The third and final impact of inequity-driven mistrust that we identified in our data was the increased frustration associated with the actors involved in a humanitarian response. Similarly, like health systems, we also observed instances of a broken relationship between communities and humanitarian or civil society organizations – or the response as a whole - because of the frustration associated with inequity-driven mistrust. This frac-

tured relationship can negatively impact agencies' capacities to create and implement programs that are connected to wider humanitarian responses. One of the humanitarian agencies that we interviewed in Iraq explained how, they felt that in many instances, the relationship between the agency and the community was soured before they had even started their work.

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“It is incredibly difficult when you approach people with genuine intentions, enthusiasm, and a readiness to help, but they respond with negative comments. You and your agency are dedicated to carrying out your job, yet you encounter a strained relationship with them even before any interaction takes place. This greatly impacts our health interventions and poses significant challenges in our efforts to provide the best possible assistance to them.”

- Humanitarian Agency, Northern Iraq

Communities' negative experiences with certain organizations can impact the entire sector. In some instances, there can be generalized frustration with the ways in which certain practices or programs have negatively affected communities. The associated mistrust can impact the work

of new organizations even if they were not the ones involved in those practices. We captured multiple instances in which it became paramount for organizations to reestablish those trust relationships by differentiating themselves from the sector at large.

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“We have received reports that some beneficiaries refuse to open their doors during door-to-door visits due to negative experiences with other non-governmental organizations operating in the field. Therefore, it became crucial in certain areas to rebuild trust and reintroduce our work as an agency distinct from other organizations working in the region. This was done to facilitate smoother interventions and enhance community acceptance of our work.”

- Humanitarian Agency, Northern Iraq

The frustration with humanitarian response was also influenced by the timeliness and sustainability of implementation. During our interviews in Iraq, we encountered significant frustration related to the abrupt withdrawal of humanitarian funding from IDP camps in the north. The lack of program continuity, and poor communication and transparency accompanying these actions, can contribute to a sense of sudden abandonment, leading to rumors and perceptions of inequity. This issue

is partly a result of a weak connection between humanitarian and development programming, which makes transitions feel abrupt. In Iraq, communities expressed concerns about the lack of communication regarding what would happen once humanitarian funding was cut. All these frustrations contribute to feelings of inequity and injustice, further impacting the relationship between communities and future humanitarian programming.

Section 3

Recommendations to mitigate, address and acknowledge inequity-driven mistrust

Mistrust is built on numerous factors. We have attempted at bringing inequity into the equation and understand the role that instances of injustice and unfairness play in trust relations of vulnerable groups amidst an emergency. As such, we have identified several drivers through which inequity contributes to creating or maintaining mistrust in health and humanitarian responses, the actors who lead them and/or the information provided pre and amidst an emergency.

In this section we provide a series of recommendations on how best to address – or attempt at mitigating – the roots of inequity-driven mistrust. These recommendations also provide positive practices that are already in place in some of our case locations and contribute to promoting trust among actors and communities affected by crisis.

The recommendations below listed were identified in conversations with our Key Informants from Colombia and Iraq. They also built on the learnings of the Rooted in Trust project since

the beginning of the COVID-19 pandemic.

The recommendations are listed following the logic of the first section (Drivers through which inequity affects trust in information). These drivers represent the tension points that health and humanitarian actors should take into consideration when designing and implementing programming for vulnerable communities experiencing instances of inequity. We understand that these expressions of inequity are complex to address. There are no magic bullets that can balance historical and deeply rooted power relations impacting these communities. However, we hope that actors operating in humanitarian contexts acknowledge these intangible factors, that indeed can have profound implications in the outcomes of emergency responses. We hope these recommendations will help humanitarian and health organizations in adapting practices, not only to ensure the information provided is trusted, but also in considering the ways in which inequity-mistrust can ultimately impact their work.



* Recommendation 1

Responding to: Structural Inequities

Historical Marginalization

Consider past and lived experiences. Acknowledge how the past can have a very real impact on a community's relationship with public health and emergency interventions today. It is important to consider the histories of oppression or discrimination that permeate today's practices, not only to promote new relations of trust, but also to ensure communities can recover the power taken from them. As such, it is important for actors to evaluate power relations and consider the dynamics at stake in the settings where they operate.

- * Consider organizing FGDs with community members to understand how they perceive the humanitarian response and what value they perceive on your organization's work – ultimately, listen to what communities need from you.
- * Do not step back from criticism and be open to uncomfortable feedback that questions your practices and role.

Ensure dialogue between Western and indigenous/traditional knowledge systems. The Western knowledge paradigm with its ways of understanding and recording reality has often invalidated or questioned local and indigenous knowledge systems that encompass differing ways of transmitting knowledge than the scientific approach. Yet, for many communities in the Global South, these cultural forms, systems of classification and ritual/spiritual practices inform day-to-day decision-making, including in times of emergency. Opening the door to conversations on this is the first step to respecting this fundamental aspect of people's lives, recognizing the diversity of care seeking practices and ultimately steer trust among communities.

- * Include herbalists, traditional healers, and spiritual leaders in your network of frontline partners so they can channel guidance on available health services and prevention measures in their healing practices.
- * Ensure these actors are consulted when designing Risk Communication and Community Engagement (RCCE) strategies so they can bring the perspective of traditional healing and inform your work.

Gaps in access to quality services

Consider how gaps in the access to quality health services contribute to exacerbate further mistrust in health actors and their guidance. It is difficult for communities to trust health actors that have continuously failed at delivering services and protecting them. As such, it is important to understand the relation with local and national health authorities, as well as local hospitals or health centers – aiming at rebuilding the broken promises and violated values.

- * Hold FGDs and identify how people feel about health services in the area, discuss the limitations and options available to them so they can manage real expectations.
- * Discuss with national and local health actors the importance of building trust with the public ahead of an emergency through inclusion and equity in health service delivery.

* Recommendation 2

Responding to: Inequity During Health Response Inequity

Tokenistic and non-participation

Acknowledge existing capacities among the community. Communities across the world have vast capacities and structures to respond to adversities and learn from them, just as they have been doing throughout history. Assuming that humanitarian professionals always need to be flown in from abroad is an acute mistake installed in colonizing and paternalistic practices of humanitarian aid. While sometimes there may be the need to bring additional expertise from other parts of the world to complement the response, it is first and foremost important to identify and respect those already operating at the local level – this will not only contribute to a rich exchange of learnings but it will also support evening out power relations between international actors and local ones, building a sense of trust on both sides.

- * Conduct a mapping of local response actors' capacities ahead of an emergency and keep a continuous dialogue with them, supporting knowledge transfer and information exchange.
- * Ensure that community structures are prioritized for response before outsourcing contracts or services to outsiders – when done, ensure that they are adequately coordinated with community actors.
- * Train community members when capacity gaps are identified so that they can be at the forefront of the response as implementers – this will contribute to reduce mistrust in your intentions, as it recognizes communities' agency to define the response in the most appropriate way.

Ensure continuous participation of communities in preparedness and response plans. Communities are well positioned to inform technical actors about priorities, needs and strengths that can guide preparedness plans at the hyper-local level. They can also inform you about communities' practices that can impact emergency plans implementation. For this reason, it is essential having communities at the table of decision-making.

- * When preparing emergency plans, get in touch with CSOs and community leaders who can inform you about the relevance and adequacy of those plans.
- * Consider participation from representatives of vulnerable groups to identify risks and barriers affecting different demographics such as women, youth, people with disabilities, older people or LGBTQI+ communities.
- * Social listening and rumor tracking efforts can provide valuable insights into a community's needs, concerns, and risks. Consequently, utilizing the findings derived from social listening to influence the design and implementation of preparedness and response plans is a complementary approach to ensuring the inclusion of community voices in programming.

■ Top-down approaches

Provide options and avoid imposing one-way solutions. Trust can only come into play when the individual or community has the freedom to act and decide on the measures that affect them, on the ways services are delivered or even on the strategies to confront an emergency. When given the opportunity to engage in dialogues about options, we open the door to recognizing common goals with acknowledgement of different capabilities and levels of autonomy.

- * Consider the different possibilities of communities to take actions on the instructions given – provide options that are actionable.
- * Promote two-way trust by providing options and acknowledging that people will ultimately take the decision that makes more sense for their realities.

Conduct social listening/collect feedback and act on the findings. Communities are continuously asked to respond to questions, fill in forms, provide feedback and take part in FGDs. But they rarely see the outcome of those interactions transformed into something meaningful for them. That undoubtedly triggers suspicions and mistrust on humanitarian's intentions and brings back memories of extractive colonial past. To address this, it is important to define protocols and follow-up structures on community data as part of feedback loops.

- * When gathering community data, explain why you are collecting that data and allow community members to inquire further on its use.
- * Before setting up any social listening or feedback mechanisms, make sure you have the proper systems, organizational culture, and power of adaptation to take relevant action on the data.

- * Share the findings with communities, listen to their ideas on how to address the main issues identified and ensure there is scope in your program to adopt community solutions – or to provide support for communities to implement them themselves.

Maintain long lasting relations/collaboration. Being present in the community should be an ongoing effort - before, during and after the emergency. It is difficult to build solid relations with community actors if humanitarian actors jump in with their own expectations and ways of doing things prior to an emergency and leave the place right after without proper exit strategies. It is thus essential to invest resources to build truly collaborative approaches that can evolve along the different phases of the crisis.

- * Include local media in relevant coordination platforms such as RCCE or Media Working Groups to ensure two-way dialogues on priorities, policies, response actions and media's part in it.
- * Allow feedback and criticism from media practitioners– they are also part of the community and can guide you on what works and what doesn't when attempting to reach different audiences.
- * Transfer capacity and tools when leaving and ensure local media partners are equipped to fill the gaps.

■ Questionable intentions

Be transparent about processes and intentions to maintain trust. Considering the processes of marginalization and troubled histories that vulnerable groups often face, it is important for humanitarian actors to be open and transparent about intentions, walking communities through every step of the way.

- * Identify trusted entry points to the community who can explain in a relevant way, not only the “what” and “when” of public health measures or service delivery but also the “why” and “how” of the different decisions taken during an emergency. Be clear about the criteria used to make certain decisions and ensure there is also space to discuss “who” is involved (including who is paying for it).
- * Advocate for and train public health authorities to maintain a transparent approach to their communication during an emergency, acknowledging uncertainty and being open to questions.

* Recommendation 3

Responding to: Inequity as part of the information response

Access to relevant information

Build preparedness of the information ecosystem for health emergencies. Just as public health actors focus on strengthening health systems capacity for crisis preparedness, they should also focus on strengthening the information ecosystem immediately related to vulnerable groups impacted by health emergencies. This means mapping out all relevant actors in advance, conducting assessments that inform about the community information use and access dynamics, identifying the challenges for collaboration among the actors involved and putting in place mechanisms to address gaps way in advance to the emergency.

- * Formulate RCCE strategies that incorporate all actors within the information ecosystem i.e., media and journalists, CSOs, community structures, local health workers, local health authorities, humanitarian actors and other non-traditional information providers.
- * Identify the main gaps that impact optimal collaboration among these actors and

build the bridges in advance so health expertise and public health guidance can reach communities in the most appropriate way amidst an emergency.

- * Define clear roles and responsibilities among all the actors, identifying spaces for complementary work and needs for enhanced coordination.
- * Train actors within the information ecosystem on community engagement and the value of social listening, so they can better identify communities’ information needs.

Provide contextualized, localized, and actionable information. Avoid providing general messaging by supporting communities to produce information products that are relevant for their peers. It can be done by supporting local media outlets and CSOs (and allowing them flexibility and independence to cover the issues that are important to them), as well as including community members as part of your team.

- * Support communities to lead the production of information products and formats that allow two-way communication (for example: interactive radio shows, online live drama shows with space for comments, community gatherings, etc.).
- * Train communities to consider the needs and barriers of specific groups to access and use information – tailored approaches are important to ensure information reaches everyone amidst a crisis, despite the risks faced.
- * When possible, identify options for local health experts and bring their expertise to the community – people may trust a family doctor that can relate to their immediate references more than a WHO top-level expert that is unaware of local specificities.
- * Social listening and rumor tracking can tell us a lot about the needs, concerns, and risks that a community is facing. As such, the learnings derived from social listening can help in the provision of contextualized and actionable information.

Production and dissemination of information

Pair the dissemination of information with availability of services/clear actions along the different stages of the emergency response.

Creating expectations or building demand about a service or treatment that is not available will only create frustration. Keeping silent about services that are indeed available may create suspicion on interests. It is thus important to pair proper communication initiatives with the stage of the emergency response, the availability of services and the options of access to them by vulnerable and marginalized groups.

- * If services are not available, or there is unclarity about next steps in the humanitarian response, do not remain silent but rather explain why this is happening and what organizations are doing to address the gaps.
- * Advocate to health and humanitarian partners about the benefits of informing communities throughout adjustments in the humanitarian response – they better keep the conversation going and acknowledging uncertainty than leaving space for misinformation and mistrust from communities.



Conclusion.

The COVID-19 pandemic has underscored the detrimental impact of misinformation and mistrust of health information on health systems. This paper aimed to address the gaps in understanding the role of inequity in driving mistrust in health information among at-risk communities in humanitarian contexts and its impact on “infodemic” management and health emergency response. Through case studies conducted in northern Iraq and the Colombian and Brazilian Amazon regions, the research identified three main drivers of inequity-driven mistrust: structural inequities, inequities during the health response, and inequities associated with the information response.

The findings revealed that at-risk populations in low-income settings experience inequalities at various levels, often rooted in postcolonial structures of knowledge production, unequal health systems, and disproportionate distribution of medical supplies. These inequities contribute to mistrust in health information, leading to impacts on the ways that communities engage with the official information response, health outcomes and behaviors, and the relationship with health systems and humanitarian responses.

To mitigate the impacts of inequity-driven mistrust, several recommendations were

proposed. These included acknowledging past and lived experiences, engaging in dialogue between Western and indigenous/traditional knowledge systems, addressing gaps in access to quality services, recognizing and respecting local capacities, and fostering meaningful community participation.

While this research sheds light on the drivers and impacts of inequity-driven mistrust, it also acknowledges its limitations. The study was conducted in a limited number of contexts, and further research in diverse humanitarian settings is necessary to broaden perspectives and understand contextual complexities. Language and translation challenges were also present, particularly in the Vaupes context, which should be considered when interpreting the findings and conducting future research.

In conclusion, this research highlights the importance of addressing deep-rooted inequities to mitigate the effects of mistrust in health information among at-risk communities. By recognizing and actively working to address the drivers of inequity-driven mistrust, health and humanitarian actors can improve “infodemic” management efforts and health emergency responses, ultimately promoting trust and better health outcomes for vulnerable populations.

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