Field Report

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Misinformation in Humanitarian Programmes: Lessons from the MSF Listen Experience

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Abstract

While health misinformation is important to address in humanitarian settings, over-focusing on it can obfuscate a more holistic understanding of a community's needs in a crisis. Through Médecins Sans Frontières' experience of deploying a platform to tackle health misinformation during the COVID-19 pandemic, this field report argues that, while important, health misinformation became a diversionary topic during COVID-19, which represented a lack of trust between communities, humanitarian organisations and health institutions, rather a fundamental obstacle to effective humanitarian interventions.

From our practitioners' viewpoint, we reflect on the deployment of the 'MSF Listen' platform in our programmes and how it evolved from a purely misinformation-focused digital tool to a broader workflow and approach to understanding community needs in crises through accountable management of community feedback.

Keywords: misinformation; community feedback; humanitarianism

Background

In June 2020, a few months into the COVID-19 pandemic, the medical humanitarian organisation Médecins Sans Frontières/Doctors Without Borders (MSF) initiated a project to better understand and respond to health misinformation in humanitarian settings. Along with the global surge in morbidity and mortality, COVID-19 brought a deluge of health misinformation – including in the communities that our teams work in across the world. To address health misinformation, we created 'MSF Listen' – a rumour and misinformation-monitoring platform based on software written by The Sentinel Project (thesentinelproject.org). As both a web- and mobile-based platform, MSF Listen is a workflow and an implied methodology for dealing with health-related rumours and misinformation. Health data can be construed in many different ways (Stellmach *et al.*, 2023, in this issue), and the data in MSF Listen is qualitative health data about community perceptions of well-being and disease, and health services in multiple contexts where MSF works.

At present the MSF Listen user base is constituted solely of MSF staff. The platform allows users to upload feedback from communities and patients that is gathered through standard community engagement initiatives pertaining to MSF contexts. The idea is to incorporate this feedback into operational decision-making processes so that MSF operations are iteratively adapted to the needs of a given community. For example, feedback collected during a community discussion concerning an upcoming vaccination campaign – after being

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anonymised, uploaded and triaged – can inform MSF as to how to best implement the campaign. The data in the platform conforms with GDPR regulations.

MSF Listen was first deployed as a pilot project in September 2020 in three distinct MSF contexts: a tuberculosis programme in Tajikistan, a maternal and childcare programme in Afghanistan, and a primary health care programme in northern Somalia. Thereafter, it was deployed region-wide for COVID-19 programmes in Latin America, then in 2022 for Lassa Fever in Nigeria and cholera in Haiti. The project had three primary aims: to upskill MSF staff in the management of health-related misinformation and rumours; to create a community of practice that would encourage knowledge and solution sharing; and to improve the effectiveness of tracking methods for – and the response to – rumours and misinformation.

COVID-19 Health Misinformation: The Beginnings of a Solution

The scoping around, and design of, MSF Listen occurred in parallel with the first wave of problematic COVID-19 misinformation in the summer of 2020. At the time, MSF operations in multiple countries were struggling with the consequences of COVID-19 misinformation all over the world. In Yemen, misinformation about isolation centres and COVID-19 treatments demonstrably affected people's health seeking behaviour. An MSF operational update from Yemen in August 2021 notes, 'People fear that they will receive lethal injections, or even be detained against their will if they visit a COVID-19 centre' (MSF, 2021).

The rumour about lethal injections is a persistent one, which has and continues to spread through WhatsApp forwards in humanitarian networks (Al-Maghafi, 2021). In Haiti rumours about lethal COVID-19 vaccinations, or rumours that only foreigners can have COVID-19, changed peoples' health-seeking behaviour. This resulted in delayed presentation to and increased mortality in MSF-run COVID-19 clinics, and a refusal of injections leading to low vaccination rates (Moloney, 2020). In Niger, hesitancy about COVID-19 vaccines stemming from confusion over the efficacy of government-led vaccination campaigns affected concurrent meningitis vaccination efforts, which had been successful in the past (Karsou, 2021). In Sierra Leone, MSF staff witnessed how rumours about rogue travellers delivering lethal COVID-19 injections under the guise of vaccinations were changing the health-seeking behaviour of communities. Presentation rates for routine vaccinations for children under five dropped as a result (MSF, 2020).

Over this period, the MSF Listen team conducted eight interviews with field teams to better understand how they dealt with such rumours and misinformation. Individuals holding various roles were consulted (Health Promoters, Project Coordinators, Field Communications Managers, Advocacy Managers, Epidemiologists and Communications Advisors) across a range of contexts (Afghanistan, Senegal, Haiti, Malaysia, Pakistan, Sierra Leone, Somalia and Yemen).

Our scoping interviews confirmed that rumours pertaining to fear of foreigners bringing COVID, or vaccines as lethal injections in MSF hospitals were indeed common. However, most interviewees confirmed that these health-related rumours were still manageable, in that they did not impact the daily functioning of MSF services.

Yet there was an almost unanimous desire for more visibility across MSF in how rumours and misinformation are managed across common contexts. For example, where certain communities, with similar religious or ethnic characteristics, are persistently sceptical about COVID-19 vaccine efficacy, could MSF facilitate collaboration for teams across such contexts to advance potential solutions? A clear need was also expressed for a 'best practices framework' that respected the context-specific nature of rumours and misinformation. Teams used rudimentary tools – Microsoft Excel and Word, as well as handwritten notes – across contexts, but there was a consensus that a comprehensive tool that facilitated active, daily interrogation of their contents would be useful; it is easy to forget about a notebook in a desk drawer during an emergency.

This scoping process was concluded in September 2020, whereupon MSF adopted the aforementioned Sentinel Project software. This software was designed to contextualise and mitigate misinformation through community involvement. For MSF's purposes, however, we adapted the methodology to improve MSF's own collection and analysis of health misinformation and rumours that might affect the health-seeking behaviour of the communities we serve in real time, with offline functionality and a low barrier to access for staff ill at ease with digital tools. MSF Listen's data set is purely qualitative and mostly health-related, and the examples below illustrate two important insights related to trust and the cultural embeddedness of health-related information.

Health Data and Trust

Whether in the form of rumours, questions or calls to action, the data within MSF Listen informs MSF of health-related decisions made by communities it serves – as such, it is health data. Though the development of

MSF Listen was not explicitly informed by cautionary tales of humanitarianism's over-fetishisation of technology (Currion, 2019 in Stellmach *et al.*, 2023, in this issue), the intention from day one was to avoid falling prey to the innovation-as-solution approach to misinformation and rumour management (M. James, personal communication, 3 August 2020). The implementation of MSF Listen in every context was accompanied by an interpersonal, analytical process between users – led by the implementers – to dig into the origins of rumours and misinformation that might affect people's health seeking behaviour in a crisis.[1] The importance of the platform for MSF is that it brings teams together.

This process was an intentional move away from a purely fact-checking approach, which has been the go-to strategy of media organisations, big tech and certain humanitarian actors to counter misinformation during COVID-19. Such a strategy is guided by the hope that people who believe misinformation will recognise the error of their ways, so long as they are provided with facts.

To be sure, providing fact-based information in humanitarian settings, which can often be characterised as broken information ecosystems, is essential. It creates the foundation upon which to build effective and useful health messaging in crises. Yet, while facts are necessary, they are not sufficient as a solution. The trustworthiness of a piece of information is just as important as its accuracy. How a piece of information reinforces or threatens people's identity, and the trust they place in various (local and international) information actors, are forces that mediate their relationship with information (Babei, 2020).

The role of Imams in northern Somalia is a good example of how trust mediates belief in a piece of information. In February 2021, an MSF health promoter (HP) in Somalia uploaded something recounted to him by an influential local imam: 'The COVID-19 vaccine contains pork-derived gelatine in its ingredients.' This was relayed by the imam to his following regularly, resulting in local scepticism of all vaccines. However, over the course of a few conversations, the HP noted that the imam eventually changed his perspective, claiming that taking the vaccine was more important than the concern about its ingredients. This change coincided with increased vaccine uptake in the region.

The Cultural Nature of Facts

Fact-checking, and our understanding of what counts as misinformation, is also culturally and epistemologically loaded. Assessments of what counts as misinformation, particularly health-related misinformation, are informed by western biomedicine. Thus, fact-checkers often cite information by authorities such as the US Centers for Disease Control (CDC) and the World Health Organization (WHO) to stake their claim; cultural and medicinal practices that fall outside biomedicine's regimes of evidence and validity are natural objects of suspicion.

In March 2021, as part of the Somalia pilot of MSF Listen, a user uploaded the following onto the platform: 'Culinary herbal related remedies prevent/treat covid-19.' This 'rumour' originated from *cilaaj*, or traditional healers, in Somalia, who promised to prevent/cure COVID-19 with their concoctions. This was not dissimilar from herbal and unproven remedies touted in countries such as Madagascar, Venezuela or the USA by their respective heads of state.[2]

After the rumour was uploaded onto MSF Listen, a brief exchange ensued. One user provided important background information. They wrote, 'healing has become a way to earn income, and unregulated conditions have created a jungle-like healthcare space.' Another user wrote, 'The problem here is that when people use the herbal remedies made in *cilaaj* they would stop following the COVID-19 guidelines for infection control', doubtless echoing the concerns of many in the medical and scientific community worldwide.

These comments clearly highlight the pitfalls of believing unproven cures: traditional healers have financial motives (not unlike big pharmaceutical companies) and following their advice can result in harms to one's health. But to have deployed a purely fact-checking based approach to warning this community about the risks of unproven cures would have overlooked the fact that a proliferation of traditional remedies, in this instance, was a product of a broken economy and a lack of alternative therapies. While such healers may not provide the right medical solution, we have learned to be wary of the impulse to treat unproven cures and 'traditional medicine' as misinformation. When MSF communicates about herbal or unproven remedies and their suppliers, we are engaging in what is, in effect, a cultural encounter between different epistemologies (ways of knowing) and ways of doing medicine, in which the local knowledge system – and the implicit trust it engenders within a community – can clash with MSF's biomedical objective to save lives at all costs. Such an unwavering commitment to a biomedical regime of practice may come at the expense of a deeper understanding of a community's health seeking behaviour, and perhaps even their trust. Thus, even as we seek to protect patients from the harms of misinformation, we must take care not to dismiss the cultural and medicinal practices that are excluded from western biomedicine's frameworks. Doing so in resource limited settings may deprive communities of an important healthcare option and erode trust in the various health actors who claim to serve them.

Discussion

Reflecting on the MSF Listen experience, we identify three key insights about misinformation, its management and its implications for health-related programmes.

1. **Systematic, digital information collection and sharing facilitates cross-organisational learning, leading to more effective strategies to counter misinformation and rumours**

A key objective of the MSF Listen platform was to improve MSF's institutional memory in the management of misinformation and rumours. During scoping interviews for this project in 2020, MSF staff explained how 'static' resources did not allow them to easily spot patterns and trends in the data they held.

MSF Listen was therefore designed to animate information that users consider important within a secure online space. Users are prompted to provide attributes related to the upload – including the topic, date and time, and who should be 'assigned' to handle it. The submissions are entered into a database, visible to all registered users, which is now a steadily growing qualitative repository of rumours, misinformation and other kinds of community feedback. While the software was designed to enable community members direct access to the reporting process, MSF staff are – at present – the only registered users. The platform also facilitates analysis of uploads by theme, location or frequency. For example, rumours reported in Somalia in 2022 could be tracked according to the onset of a new wave of COVID-19, showing how certain rumours resurface in parallel with COVID-19's resurgence.

Within MSF, rumour management has remained largely confidential to the person, place and time of the process. For instance, rumours collected in the context of a vaccination programme for displaced persons in Somalia may not be available to a programme carrying out vaccinations for refugees Kenya, even though it might be beneficial to the latter. This is largely due to infrastructure issues; MSF is a huge, somewhat decentralised organisation that often applies an 'emergency mindset' to funding decisions for support projects like MSF Listen, every investment being weighed up against the question 'is this more valuable than investing in [insert humanitarian emergency]?' MSF Listen helps to address this by facilitating cross-organisational and programmatic learning that does not encroach on the divergent operational strategies of different teams.

MSF Listen also mitigates against the structural challenge of poor information sharing by linking MSF colleagues in different locations to information that is relevant to them at a given moment. For example, the platform features an internal 'scraping' system, whereby a new upload is scanned against pre-existing uploads and if a match is found the new upload becomes a 'sighting' of an older one. This means that if 'Ethanol cures COVID-19' is uploaded five times over three years in four locations, it is represented as one upload with five associated sightings at different times in different places. This enables a more nuanced analysis of the data. Such a process is key to advancing organisational learning as users across MSF engage in shared problem-solving processes, their solutions and recommendations also being pooled in real time to further refine best practices.

2. **An interdisciplinary approach is key to ensuring misinformation, rumours and community feedback are managed effectively**

Where rumour collection and misinformation management activities are being implemented in MSF, they are typically the responsibility of a particular team (health promotion or project management), or individuals (typically locally hired staff with ties to the community). However, MSF Listen brings together a cross-section of users, drawn from a variety of professional backgrounds (medicine, epidemiology, health promotion, anthropology, communications) and holding different roles within the organisation, to collectively analyse and respond to misinformation that circulates in communities. This was an explicit result of the scoping interviews, in which respondents almost unanimously expressed a desire to participate in a community of practice for handling health-related rumours and misinformation.

Our experience using this interdisciplinary approach to manage misinformation and rumours has shown that when the analytical process around a rumour is socialised across a team with varied skillsets, the team felt better prepared and more closely aligned in creating solutions. This was borne out in a user feedback survey undertaken in September 2021, and again through preliminary results of an independent evaluation of the platform carried out in January / February 2023.

An example from Somalia about mask adherence during COVID-19 illustrates this well. A pervasive refusal to wear a mask in a specific region of northern Somalia close to an MSF clinic was – somewhat lazily – attributed to the notion that the community just thought masks were ineffective. Yet via an interdisciplinary process, facilitated in real time in MSF Listen, our team determined that the root cause of this behaviour was most likely distrust in the Somali government's ability to regulate personal protective equipment (PPE) imported from China. The platform workflow prompted a

dynamic investigation into the problem by attributing responsibility to team members with different expertise; an advocacy manager contributed an understanding of national level socio-economic relations between Somalia and China, while community liaisons shared a ground level understanding of locals' concerns.

3. Rumours and misinformation form only part of the picture, which can be misleading

There is healthy literature on the limits to correcting misinformation in humanitarian settings (Chandler *et al.*, 2014; Enria *et al.*, 2016; Wilkinson *et al.*, 2016), which guided the MSF Listen implementation methodology. However, the use of the platform in multiple settings reinforced what had been cautioned in theory.

For example, in July 2021, a user in Bolivia uploaded: 'The face mask makes us feel sick', as reported by a community member at an MSF clinic. At the time, rumours that masks did not prevent COVID-19, or that they caused COVID-19, were widespread, including in places where MSF Listen has been deployed. However, this example provides the feedback of a community member on mask use, rather than misinformation about mask use.

Likewise, in November 2020, an MSF Listen user in Somalia uploaded the following: 'The thermometer gun is a source of COVID-19 transmission.' While temperature guns are not a known vector of COVID-19, the information reflected community perceptions of MSF's intervention, and their concerns about it. This perception resulted in reduced rates of presentation at the clinic in question – the worst possible of all outcomes. After a discussion on MSF Listen, the project team decided immediately to do away with thermometer guns in the facility, which led to marked increased presentation rates within 36 hours.

In both examples above, the mistakenly labelled 'rumour' was in fact providing feedback about a given MSF healthcare intervention and, in some cases, possible ways to improve patient outcomes. Multiple instances of this type of mistaken categorisation prompted a deeper interrogation of the platform's scope, leading to a lengthy adaptation process which ran from January 2022 – March 2023. Spearheading this process was a strategic and interdisciplinary working group of community feedback advisors, anthropologists and evaluators whose collective efforts, in conjunction with extensive user feedback, resulted in a full rebuild of the MSF Listen software in December 2022. Perhaps more foundational, however, is that MSF Listen provided a space and process for teams to interrogate such informational problems, and to develop strategies to address the issue.

This is perhaps the most significant learning of the MSF Listen experience: 'rumour management' processes can overshadow the underlying contextual reasons that result in rumours – fear, uncertainty, mistrust and their role in dealing with people's health. In other words, a focus on rumours alone – as was the initial case of the MSF Listen experience – detracted attention from their cultural embeddedness and specificity. The narrow focus on managing rumours risks de-socialising information, with a potential outcome that binary, value-oriented conclusions (i.e. this rumour is 'true' or 'false') reinforce mistrust and power imbalances between communities and health actors.

In order to effectively deal with these root causes, a broader, more holistic, socialised understanding of the information landscape is required. MSF Listen has therefore evolved into a community feedback-oriented platform, with a greatly expanded scope beyond rumours and misinformation. In its new iteration, MSF Listen will encourage the capture of all kinds of feedback from praise, patient experiences, calls to action for MSF support and questions about health interventions. This shift – adapting how we categorise, analyse and triage information we receive from communities – is also about a change of mindset. By taking the time to listen to and respect the myriad voices of communities in humanitarian settings, we intend to build more nuanced and equitable relationships with communities that help to build trust by seeing information in a more holistic and culturally embedded way. As an organisation, MSF strives to co-design humanitarian operations alongside the communities it serves – where possible – and the new version of MSF Listen is an important step along that road.

Conclusion

In this field report, we have shown how health-related misinformation is a growing challenge for the medical programmes that MSF operates, and for the humanitarian sector at large (Bruns *et al.*, 2022). It can erode trust in healthcare interventions and negatively affect people's health-seeking behaviour, thereby resulting in poor health outcomes. Yet the methods used to counter misinformation can also exacerbate the problem if they fail to address the whole information landscape in which misinformation thrives. Digital tools and workflows such as MSF Listen can be useful in obtaining a more complete understanding of health-related

misinformation and rumours – by capturing more information and sharing it across teams/roles (aka disciplines) and across contexts. This helps to better inform strategies to counter misinformation. Our experience suggests that the processes by which such methods are implemented are equally important, and have a bearing on the result.

The MSF Listen experience has shown us that horizontal, multi-disciplinary approaches to managing, and following up on, health misinformation in humanitarian settings is an effective method for improving health-seeking behaviour and building trust with communities. Rumours and misinformation act as signals that contribute to our understanding of community needs, and while countering them is important, adapting humanitarian interventions to fit with the information ecosystem is more important. As such, in order to be truly effective, the work of countering misinformation must be framed within the broader concept of community feedback and executed with epistemic and cultural humility. Failing to do so risks perpetuating broken bonds of trust between communities and humanitarians.

Notes

1 In MSF's Somalia projects, to date, around 120 weekly meetings between MSF Listen users have occurred to interrogate the platform's content in an interpersonal way.
2 Nicolás Maduro, the president of Venezuela, was eventually suspended from Facebook for violating its misinformation policy after he promoted Carvativir, while Donald Trump has been identified as the key node in global COVID-19 misinformation propagation (Evanaga *et al.*, 2020).

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