

Workshop 3: Modeling Intervention Acceptance for Disease Mitigation

Publication Note: This document is a “white paper” created as background for and a summary of discussion by participants at a virtual workshop held on April 28, 2023. The workshop was supported by the National Science Foundation Predictive Intelligence for Pandemic Prevention (PIPP) Initiative. The contents of this document are the opinions of the authors and participants.

Background

During the COVID-19 pandemic, the public health and scientific communities identified a number of effective interventions—including vaccines, mask wearing, and social distancing—to protect the public. However, the potential of these interventions for disease mitigation was significantly diminished by what the World Health Organization (WHO) declared to be an “infodemic,” or, “an outbreak of misinformation” that accompanied the pandemic. In Workshop 3, we explored the role of health (mis-)information in pandemic prevention and mitigation. Drawing on the expertise of leading researchers across academia, community and non-profit organizations, journalism, and public health, we focused on four key aspects of health communication that have significant implications for our ability to limit parallel health information crises, prevent future infodemics, and—by proxy—prevent and attenuate future pandemics. The workshop took on a panel format, with panels organized by broad topic and comprising of three to four experts across domains related to the subject matter at-hand.

To understand the dynamics and harm of so-called “infodemics”, we begin by exploring how (health) information spreads in a variety of media ecosystems. Information spreading is a complex phenomenon, for which predictive models and causal explanations have been notoriously difficult to build [1]; however, understanding the capacity for information to mobilize communities and change behavior is essential for predicting its reach and impact. In this white paper, we focus specifically on the harms and complications introduced by health misinformation—a problem so pressing that it was the topic of this year’s Nobel Prize Summit. While solutions exist, there is little consensus on what should be considered as misinformation and even less regarding how to control its spread. Differences in attitudes towards these questions reach far beyond simply ideological differences, and concerns exist regarding controls efforts that would disproportionately oppress already marginalized voices [2]. We pay special attention to these marginalized and underserved populations, including Black, Brown, and Indigenous communities, which have witnessed higher rates of infectious disease [3] and medical mistrust [4]. More broadly, we focus on communities facing factors such as language barriers, limited resources, or other circumstances that have resulted in their exclusion from science and health communication. We go on to generalize to broader challenges and problems with science and health communication and outreach that were revealed during the pandemic. After discussing the possible insufficiencies that may have contributed to the rise of misinformation since 2020 and science communication’s inability to stop it, we present a better course of action.

Understanding (Health) Information Spreading

Information spread has often been likened to the spread of epidemics on networks, providing a useful framework for analysis. However, the expert panelists quickly agreed that simple network contagion models of information diffusion fail to capture crucial details. Broadly, one panelist postulated, the shortcomings of these models come from individualistic, agential perspectives on information spread, as well as a complete neglect for the sea of information which is ever-present in the modern day information ecosystem. The presence of multiple interacting information "contagions" (in this case, competing health information and misinformation) is common, and these models lack the capacity to reasonably account for this. While diseases can be rather effectively modeled by a node "occupying" an infected state, information is not so simple nor so static. Moreover, simple network models lack an unfathomable amount of social-contextual information that can only be understood by studying specific social systems or communities. Nevertheless, though forecasting information spread continues to pose a formidable challenge, panelists agreed that likening information spread to the spread of infectious diseases has lent a useful baseline.

To make apparent the analogies and interdependencies between disease and information spread in health communication during outbreaks, the term "infodemic" has been heavily utilized in the scientific literature [5]. Used specifically in regard to outbreaks of health-related *misinformation*, which can arise as a result of the challenges of health communication, research and modeling on the ongoing COVID-19-related infodemic has exploded. Panelists suggested that the key to improving our ability to model the spread of information—whether it be misinformation or healthy science communication—is adequate data. However, data on information spread proves to be extremely challenging. While text data is valuable, it is far more intricate and messy compared to the data used in infectious disease epidemiology. Consequently, a significant gap exists between contagion models and the reality of information spreading. Bridging this gap, panelists argued, requires on-the-ground research for data collection and verification or correction of modeling assumptions.

Humans tend to interact in groups and thus, information spreads with a certain structure within groups and heterogeneously across groups. Simple network models often do not account for this and even if they could, data is sparse and difficult to obtain. Panelists shared experiences where they had gone and met with the communities of interest, and how they found that simply the opportunity to talk to people can reveal directionality, hierarchy, and other latent organizational structure in information spreading within groups of people. When asked what they would do if they had the perfect data, the panelists quickly agreed that the challenge becomes one of spreading that information to the public in a way that promotes a healthier information ecosystem (e.g. increasing the availability of information that encourages healthy behavior, such as getting vaccinated.)

Panelists also spoke briefly on the ethical considerations of data collection and information dissemination. Primarily, they focused on the fact that scientific and medical establishments have not treated all groups equally. According to our panelist with expertise in political implications of information online, this has been well-observed in Black communities where alienation and poor communication from health organizations has led to widespread medical mistrust. The rapid proliferation of mis- and disinformation during the course of the COVID-19

pandemic has only worsened these issues. As such, panelists agreed that it is essential to acknowledge that effectively disseminating health-related information is not just a facet of the battle against a virus, nor against the forces of confusion, but also crucial to oppose the harm done by those spreading disinformation designed to disenfranchise certain populations from accessing health care advice and services. Moreover, one panelist argued that stigmatizing individuals who have been influenced by misinformation is unjustifiable, despite its commonplace in academic and medical establishments. Not only does doing so prevent progress, but it can be considered to contradict the principles of healthcare and the Hippocratic Oath, which discourage stigmatization related to viral diseases and personal health decisions.

Understanding Health Misinformation

Social media based misinformation has received considerable attention in the popular and academic press recently, but according to one panelist, understanding misinformation requires analyzing a much broader scope of issues. Misinformation stems from a complex interplay between information structures of production, consumption, and behavioral outcomes. When asked about the *actual* problem of misinformation, panelists agreed that it is not some inherent falsehood of the information being shared, but rather whether or how false claims impact peoples' behavior (e.g. false claims of a vaccine-autism connection leading to vaccine hesitancy). Moreover, misinformation is not on equal footing with verifiable information; in comparison, it is more likely to spread extensively and deeply within social networks and is difficult to measure, protect against, and correct [6].

Nevertheless, a suite of metrics and interventions have been tested and deployed to varying degrees of success. Researchers have created platform-level metrics in an attempt to quantify the prevalence of misinformation, but one panelist with experience doing so stressed that questions about what is considered "fact" often makes such measurements difficult. Panelists and attendees were quick to bring up that what constitutes factual information is rapidly changing in developing situations, such as that seen at the beginning of the COVID-19 pandemic. Examples of this include early statements that COVID-19 was being spread through foods, or that masking was not necessary or effective.

Even after misinformation has been recognized, intervening in the spread of mis- and disinformation poses significant challenges as well. Our panelists suggested that considerations of scalability, sustainability, and side-effects in misinformation interventions must be accounted for. For example, fact-checking—like most post-level moderation—has limitations in scalability. Moreover, its effectiveness decreases over time and there exists a peculiar side-effect where the *absence* of a fact-check label in a system with fact-check labels can lead individuals to default to believing information as true. However, concerns regarding the extent and widespread prevalence of "backfire effects"—in which people double-down on their wrong beliefs after being fact-checked—are not empirically supported, according to a panelist with psychology expertise. Perhaps the most simple intervention is removing or down-ranking individuals or posts. While this can be successful, panelists presented concerns about the allocation of power in such actions. Relying solely on platform-level regulation is insufficient. For example, people adapt to circumvent known regulations. Our panelist with HCI expertise, however, argued that even if

people evade regulations, they nonetheless *do* help slow the spread. In addition, this panelist informed the audience of growing frustration among social media users of platforms' slow responses to misinformation. Successfully highlighting lack of expertise in certain sources has shown promise, but thus far, according to one panelist, building digital literacy seems to be the most long-lasting and effective approach. Panelists and attendees agreed that increasing individuals' *discernment* abilities amidst the vast sea of information is the most crucial part of misinformation interventions.

When discussing the abundance of misinformation during the pandemic and in health emergencies more broadly, one panelist suggested an essential component in fighting mis- and disinformation is properly managing and communicating the abundance of uncertainty regarding facts at the beginning of health emergencies. They suggested that admitting lack of knowledge regarding early-stage findings—i.e., scientists simply saying, “we don’t know”—can be very beneficial. This was broadly appreciated and lauded by attendees and panelists alike. One attendee asked if this may give rise to concerns of “data voids” where misinformation can proliferate, but panelists posited that pointing to insufficient evidence may actually fill the void by suggesting that any strong claims made lack the requisite empirical proof. Discernment regarding what studies, outlets, and researchers are given the power to determine what is fact is central to science. It is also central to the problem of misinformation. As an attendee pointed out, scientific communities have historically engaged in such discernment behind closed doors. During the COVID-19 pandemic, however, the whole world was watching.

Health Communication with and for Underserved Populations

Health organizations often fail to equally serve all communities, a reality that became evident during the pandemic. Health communication for underserved communities poses unique challenges that require tailored approaches. When asked about those challenges, one panelist suggested that communicating with underserved populations requires addressing not only issues of access to health and outbreak information, but also broader factors such as racial disparities, food insecurity, and medical mistrust. Such issues and their complex contingencies can not be theorized about; they must be heard and observed. Thus, instead of merely “creating space at the table” for underserved populations within existing healthcare conversations, panelists and attendees suggested that a paradigm shift is necessary to establish a “new table” where these concerns are centered. The focus of this table, they said, must be on addressing local, urgent, and emergent healthcare issues faced by those not adequately served by mainstream healthcare institutions.

A panelist who works first-hand with many marginalized communities stated that it is no surprise what the roadblocks are in ameliorating health outreach with these communities: a lack of funding and respect. This panelist discussed how the work undertaken to support underserved communities relies on volunteer efforts. Despite doing such important work, receiving little to no compensation for their labor and putting themselves in harm’s way, these frontline workers are often looked down upon by university faculty and those with medical degrees. The issue reflects a much broader problem of expertise: PhDs and MDs don’t trust these “regular people” to be experts, thus excluding lived experience as a form of expertise.

Other panelists brought up how the Academy's alienation of these workers makes it difficult to collect data measuring the success of messaging targeted towards underserved populations. While vaccine dissemination is relatively easy to track, measuring any strengthening or weakening of bonds between communities and organizations is not. Due to this crucial lack of data, and a reluctance to make sustained commitments to maintain relationships between marginalized communities and civic health, research, and advocacy organizations, one panelist worried that every new health emergency will require an effort to rebuild these trusted ties. Panelists agreed that investments in maintaining continued contact and conversation between communities, researchers, and public health organizations would alleviate this problem.

Some organizations that focus on health communication with marginalized and underserved communities employ "trusted messengers." These messengers effectively convey the organization's messages in ways that resonate with the community, acting as a bridge. These trusted messengers tend to be volunteer workers *in* the community of interest. One panelist's experience with trusted messengers described how these bridges make it easier to both spread health information to those with barriers to access such information and to learn about their needs. A panelist with experience working with Latinx communities pointed out that a naive assumption often made in health communication is that messages need to simply be translated into a native tongue, or align with known cultural values, to be effective. What we learn from listening to people in the community, however, is that in many cases, the messaging is not relevant at all to the problems that they are facing (e.g. precarious employment, lack of childcare, housing and food insecurity.)

All panelists stated that academics and researchers sit in a unique position to alleviate the inequalities of health communication. Data collection and funding procurement are essential tasks in research, and including marginalized and underserved communities in this process would foster long-lasting connections. Doing so would also grant crucial resources, such as more campaigns and better pay for more trusted messengers. However, in doing so, an attendee reminded the audience that it is important to avoid constantly highlighting disparities, as this can lead to apathy and hinder progress. When underserved communities seek care, constantly reiterating how their specific needs are not being met can be burdensome—something that dominant cultures and communities rarely have to do, as the existing systems already cater to their needs. Panelists concluded by restating that to better serve these historically underserved peoples, we must value and incentivize the work of advocating for equity and directing our attention towards communities that are overlooked.

Informing the Public: from Research Results to Public Impact

Inadequate science communication, both by scientists and journalists, was likely a contributing factor to the abundance of misinformation during the pandemic, according to the attendees of the workshop. Of course, effective science communication is no easy feat. One panelist, a veteran technology and science journalist, explained that journalists are faced with the difficult task of translating scientific concepts written in obtuse language into accessible information. Having to condense lengthy, recondite studies into four to six concise sentences and convince their audience of the relevance and significance of the findings is difficult even for those

scientists who engaged in the study. Another panelist went on to suggest that the difficulty of this task is exacerbated by a lack of contact between scientists and journalists, which is necessary to fill the gap between scientists' understanding of a subject and journalists' comprehension.

This particular panelist, an epidemiologist with a unique commitment to public health outreach, explained that scientists receive little to no incentive to engage with journalists or the public. Doing so requires significant effort and time away from research and is usually met with no reward from the academic establishment. Another panelist described how their own commitment to reliable health communication was unpaid and took away time from their family. As many scientists are not willing or able to make such sacrifices, knowledge gaps persist between scientists, journalists, and the public and make it tricky for the latter two to discern results agreed upon by the scientific community from misleading ones. Additionally, panelists conceded that journalists may prioritize publishing attention-grabbing results and forecasts from questionable studies rather than ensuring scientific rigor, and the public are more likely to mistakenly perceive those who present visually appealing content as experts on a subject [7]. The journalist on the panel informed the audience that these tendencies are reinforced by the proliferation of preprints, which have on occasion been used to support existing beliefs that promote misinformation.

Panelists concurred that to combat this, it is crucial for the research community to improve scientific communication by incentivizing and fostering stronger connections between scientists and journalists, as well as establishing greater transparency and trust with the public. Data accessibility is an often overlooked way of accomplishing both of these requirements. The public is sometimes assumed by academics not to have the capacity to understand scientific data but—according to the panelists—a great many do. Thus, they suggest, providing data that the public can see for themselves goes a long way in establishing trust and transparency. Moreover, as most media outlets have style guides and visual media teams, having access to data from an academic study makes journalistic coverage of that study much easier and more likely, as it allows outlets to create charts and figures that are consistent with their style guides. One panelist found success convincing state health departments to improve data accessibility amidst a lack of any federal push to do so by creating an incentive through online scorecards rating COVID-19-related data accessibility.

Creating stronger connections with the public is another quintessential part of improving science communication. But—who is the public? One panelist lent the insight that people tend to trust and listen to those who resemble them. Thus, communication with local and hyperlocal publics often proves effective. This is the reason that community bridges such as trusted messengers and pastors have been very successful methods of science outreach, but also perhaps why science communication has failed in so many instances. Panelists referred to an earlier workshop discussion about how science communication has neglected various publics and alienated them from science and scientists. Methods to remedy this have already been laid out in the discussions above: humanizing the scientific process and connecting with underserved populations.

Harking back to an earlier discussion, panelists once again reiterated that scientists should have been less hesitant to communicate uncertainties and build trust with the public. One panelist

suggested "selling the mess"—namely, turning scientific research into a compelling story that provides more transparency about the process of scientific inquiry—may be more effective than suggesting that things are too complicated to explain. When asked about *overselling* the possibilities of science—such as the possibility of eliminating transmission with the COVID-19 vaccine—panelists felt that taking preventive action based on explainable, acknowledged uncertainties is better than withholding information, oversimplifying complex issues, or making false promises. Emphasizing the need for action while acknowledging uncertainty can lead to more informed decision-making by the public, making them part of the scientific process as well. The role of journalists is crucial in this process as experts who leverage their rhetorical skills to turn science into captivating stories that reach the people, acting as a bridge between scientists and the intended publics.

Conclusion: Realigning Our Values

Throughout the workshop, two words were repeated several times: *value* and *incentive*. At the core of modeling intervention acceptance, fighting misinformation, and ultimately improving the dissemination of health information is realigning incentive structures in research to value science's primary stakeholders: the people. This means incentivizing outreach and opportunities with underserved populations to better understand their needs, as well as incentivizing further academic collaboration with journalists and publics to better communicate relevant findings and provide transparency into the scientific process. In doing so, the challenges presented in modeling information spread and preventing misinformation become much easier to face. Opportunities to converse with communities can improve models by allowing modelers insight into community-specific structural and dynamical information, thus allowing science communicators to develop culturally-focused interventions to combat misinformation and build trust. To enhance prediction capabilities of models and to increase the likelihood of intervention acceptance in publics, scientists must put greater value on those publics.

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