

Addressing the Root of Vaccine Hesitancy During the COVID-19 Pandemic

As pressure continues to mount on social media platforms to address the spread of vaccine misinformation, we aim to look at solutions to the rise in vaccine hesitancy. But to truly address vaccine misinformation and hesitancy, we need to address the underlying issues with trust in large institutions and inequity in healthcare.

By Kolina Koltai, Rachel E. Moran, and Izzi Grasso

DOI: 10.1145/3495259

s we begin to close on the second year of the coronavirus (COVID-19) pandemic, there are still deep pockets of vaccine hesitancy both nationally and globally. Particularly in the $\overline{\text{U.S.}}$, there has been widespread availability of the COVID-19 vaccine for many months and yet other countries have exceeded vaccination rates in a shorter amount of time. While there are many factors that contribute to prevailing vaccine hesitancy [1], the prevalence of vaccine misinformation and disinformation on social networking platforms is often at the heart of this conversation [2]. The question

misinformation researchers are often asked is "how can we combat vaccine misinformation online and convince people to vaccinate?" But to really dive into this question, we think it is important to understand a few things about vaccine hesitancy and misinformation. To fix vaccine hesitancy and the saliency of vaccine misinformation, you need more than improved moderation on social media platforms. You need to address difficult problematic societal frameworks and broken institutional issues including rebuilding trust in science and fixing healthcare inequity.

AN OLD PROBLEM

As long as there have been vaccines, there have been vaccine hesitant people and organizations who spread vaccine opposed propaganda. Old cartoons from the 1800s have depicted people turning into cows from the smallpox vaccine (which used cells derived from cowpox). The National Anti-Vaccination League fought against smallpox vaccine mandates in the U.K. And since the development of the first vaccines, anti-vaccine narratives have changed very little. Arguing against the safety, necessity, and efficacy of vaccines has been the playbook

for decades. The belief that the risks of vaccines do not outweigh the benefits of the vaccine is still the most common reason for not vaccinating [3].

Jumping forward to the past couple of decades into the Web 2.0 era, social media platforms like Facebook, You-Tube, and Instagram have drastically changed the way people connect with each other, particularly those who are just beginning to question vaccines [4]. While there has been a growing anti-vaccine movement in the U.S. since the infamous 1998 Lancet paper that incorrectly linked the measles mumps and rubella (MMR) vaccine



to autism spectrum disorder (ASD), social media has completely changed the ease in which people can begin finding vaccine misinformation and a community of people who support you in your questions about vaccines. We know that exposure to vaccine misinformation online contributes to increased vaccine hesitancy, and while there is certainly bot activity, misinformation's high spread rate (over debunks) is done by humans who believe the misinformation [5]. Vaccine misinformation spreads because it creates an emotional response that encourages us to share misinformation with others, progressively growing the vaccine opposed movement. This growth in the movement was evident in 2019 with a record number of measles outbreaks worldwide (and in the U.S.) and the WHO naming vaccine hesitancy as one of its top 10 threats to global health for the first time before the COVID-19 pandemic even began.

And with COVID-19, it was like throwing gasoline in the proverbial fire. Anti-vaccine groups had already been establishing a foundation of digital communities, resources, conspiracies, and evolved tactics to spread misinformation in an impactful way. The extended crisis and uncertainty of the pandemic have given prominent anti-vaccine activists the opportunity to promote widespread vaccine hesitancy, even before a vaccine was available. So while social media has certainly played a role in contributing to the persistent vaccine hesitancy we see worldwide, it is simply the tool in which people connect with other vaccine hesitant people and find and share vaccine misinformation. Even if you were able to remove all social networking platforms today, you would not address the issue of vaccine hesitancy.

VACCINE HESITANCY IS NO LONGER FRINGE

Prior to the pandemic, finding vaccine misinformation was an active search process. Your everyday user would typically not encounter antivaccine messaging as they scrolled through their social media feeds. Often, the way anti-vaccination groups

would recruit people into their spaces was by capitalizing on news stories or by sharing content to their immediate network. As an example, in 2019, there was plenty of media coverage about measles outbreaks, including both the states of Washington and New York declaring a state of emergency. With vaccines and communicable diseases in the conversation, anti-vaccine activists promoted and shared vaccine misinformation in both digital and physical spaces ranging from sharing vaccine misinformation in comment sections of news articles online to organizing anti-vaccine protests. Today, you needn't look far to find vaccine misinformation. Whether on social media platforms or news outlets, at dog parks and even your local salon, the presence of misinformation and vaccine hesitancy is pervasive and overwhelming. We used to have to go to specific vaccine misinformation Facebook groups and designated sites online, now you simply just need to turn on the television and see Tucker Carlson promoting antivaccination narratives to millions of viewers. Prior to the pandemic, having hesitancy about vaccines was taboo. Making your hesitancy known used to be relegated to private spaces online. but today publicly expressing that hesitancy can often get praise and can even provide financial gain. Being vaccine hesitant does not automatically make you ostracized, it can even provide you with a new, supportive community; and for some social media influencers, an opportunity to build their brand. Further, anti-lockdown, anti-COVID, anti-mask, anti-

As long as there have been vaccines, there have been vaccine hesitant people and organizations who spread vaccine opposed propaganda.

vaccine protests globally have been a consistent presence over the past two years bringing more public attention to the movement, especially as the conversation around vaccines focuses on mandates.

Further, there are more adults questioning vaccines than ever before in the modern era. Prior to the pandemic, most adults did not have to make a vaccine decision. While the flu shot is available each year, most people only consider the decision of vaccination when they become a parent. There have been many people who would otherwise have been called "pro-vaccine" prior to the pandemic who are vaccine hesitant about this specific vaccine. As of the writing of this article, there are many regions of the U.S. that have less than half of the population vaccinated for COVID-19. far below the needed inoculation numbers to reach herd immunity, despite the availability of vaccines. The general public en masse has been navigating the decision on whether to vaccinate or not for months putting all of us in a prime position to be vulnerable to vaccine misinformation.

But the rise of vaccine hesitancy worldwide cannot be only attributed to the pandemic itself. While certainly, prominent anti-vaccination leaders have maximized their messages with social media and the chaos of the pandemic amplified their narratives, widespread vaccine hesitancy was always something that was a possibility. This is because vaccine misinformation and vaccine hesitancy are rooted in larger socio-ecological issues in society and conspiratorial thinking. Becoming vaccine hesitant was always a possibility for a large portion of the population, and the pandemic and social media provided the opportunity to distribute an array of vaccine misinformation to the public. And as evident by the number of educators and healthcare professionals who refuse to vaccinate, educational attainment does not make you immune to vaccine misinformation.

VACCINE MISINFORMATION INTERSECTS WITH HARSH TRUTHS

The demand for vaccine-opposed content is also driven by institutional

distrust. This makes debunking vaccine misinformation an uphill battle-vaccine opposed individuals simply won't encounter or accept evidence from traditional sources that they place little trust in. In the absence of trust in science, in government, and in mainstream media, individuals place their trust in more social places, notably online communities and social media. Individuals seek out alternative "news" media sites (often fake news sites or opinion blogs masquerading as more authoritative sources), highly disputed "academic" studies questioning the efficacy or need for vaccines, and anti-vaccination health officials because they desire informational evidence for their vaccine opposition that isn't provided by "mainstream" or institutional sources of knowledge. Yet these online communities are not beholden to the same rigor or ethical commitments that have historically defined information gate-keepers and have at the heart of them no desire to change their minds. However, diminishing the presence of these communities does not rid us of the problem of vaccine hesitancy-instead we often see vaccine-opposed communities claiming that they are being censored, fueling the fire of institutional distrust and division [4].

To truly counter the demand and saliency of misinformation, we need to address the sources of distrust in our institutions. While there are no easy answers to this, we must reckon with the fact that our core institutions often do fail us and give us evidence as to why they deserve skepticism at best and distrust at worst. The lobbying power and economic ties of "Big Pharma" to the U.S. government is one such example of legitimate distrust that is leveraged by vaccine-opposed communities to further hesitancy. Even prior to the pandemic, a 2017 Pew Research Center study found only 13% of people trusted pharmaceutical companies to give "a lot of accurate information about vaccines" and only 27% think pharmaceutical leaders should have a major role in public policy about vaccines. Other meaningful examples include the failure of medical institutions to care for BIPOC (Black, Indigenous, and People

Vaccine misinformation and vaccine hesitancy are rooted in larger socio-ecological issues in society and conspiratorial thinking.

of Color) communities, the historical failures of care for women and gender minorities, and the hyper-sensationalism and partisan tribalism of traditional news media. Addressing institutional distrust requires attending to the legitimate failures of our institutions while fending off untruthful and devaluing attacks that are aimed to cement misinformation for the gain of only a few. Simply removing misinformed or problematic content without attending to the root causes of institutional distrust will only further distrust and will, crucially, fail to hold institutions accountable for their role in vaccine hesitancy.

As we embed ourselves within vaccine-opposed content we also come up against another hard truth—antivaccine content is popular as it appeals to our ideological and personal biases. This means anti-vaccination propaganda is "sticky," that it retains impact, and far spread because it often intersects with our individualized frameworks of how the world should work. Scientific and health topics such as climate change, a rejection of gender essentialism, and genetically modified foods are posed as questions of belief tied to ideological identity. And truthfully, vaccines will always be tied to politics as many countries have mandates about childhood vaccines, but the stark political division that has happened regarding scientific topics like vaccines and climate change have drastic health consequences for everyone. regardless of political party. This ties to a broader politicization of science, again driven by a growing distrust in

scientific institutions, as well as deeply embedded systems of oppression.

Anti-vaccination messages also coopt value-based messaging from marginalized communities and movements associated with them, likely an attempt to bolster the claim that supporters of the anti-vaccine movement are being silenced and oppressed. The use of "my body, my choice" has been co-opted from the pro-choice movements supporting the reproductive rights of gender minorities, yet vaccine-opposed communities simultaneously claim that aborted fetal DNA is in vaccines and support the pro-life movements. #METOO (a hashtag associated with survivors of sexual violence breaking their silence) has been used to commiserate between healthcare workers who have lost their jobs because they have refused the vaccine. "Medical rape" is another commonly used phrase, which co-opts the experiences of survivors of sexual violence, particularly women. Similarly, they have used #LOVEWINS (a hashtag used by the LGBTO+ community to celebrate gay marriage) to celebrate the unity between anti-vaccine aligned individuals and individuals who have been vaccinated but have joined the anti-vaccine movement post-vaccination. There are claims the vaccine and subsequent vaccine requirements are a "medical apartheid," co-opting the suffering that Black people face because of white supremacy. Comparisons between the Holocaust and vaccine mandates are consistently made with people wearing the Star of David at protests against vaccine passports. There are also claims that "autism is the real pandemic," along with the insistence that there is a causal relationship between vaccines and autism. Finally, fatphobia is rampant in anti-vaccine online content through the claim that changing your diet and body will decrease the risk of COVID-19 more than a vaccine could. Intersecting with the alternative health community, they push the claim that the only people at risk for COVID-19 are those who are unhealthy and overweight and therefore vaccines are not needed.

Consequently, we see popular vaccine propaganda propping up ableist

ideas (particularly surrounding ASD), and cementing homophobic, transphobic, racist, fatphobic, and misogynistic health misinformation. These narratives result in intangible harm to already vulnerable people. Systems of oppression were not devised by vaccine-opposed communities but are certainly perpetuated by them. Combating misinformation cannot be extricated from the battles for racial equality, gender equality, disability justice, and human rights more broadly.

MODERATION OF MISINFORMATION ONLINE IS INSUFFICIENT

Seemingly, there seems to be breaking news about anti-vaccine moderation and the lack of accountability from social media platforms. Just recently, YouTube announced they would be removing anti-vaccination accounts and content, however, this announcement came nearly 19 months into the pandemic with many researchers questioning if they will truly enforce the policy. Further, there seems to be no immediate plan on how to handle content that skirts policies in non-English languages. As we know with Facebook (and other social media platforms), there is often a large gap between the policy put in place by a platform and if that policy is enforced, like when Facebook "banned" ads containing vaccine misinformation but still continued to run "vaccine opposed ads." We have also seen several bombshell whistleblower stories about the lack of concern about the spread of misinformation on the part of social media company executives. Facebook has been aware of the harm of anti-vaccination content on the platform for years, and despite the ability to remove the content they take only incremental actions, if any.

Relying on moderation to address the spread of vaccine misinformation is not the solution because it relies on social media companies to effectively perform this task. What we know is that incremental moderation has not been effective in limiting the spread of misinformation. People are good at developing ways to navigate around moderation despite policies [6, 7]. Further, even when a platform decides to

deplatform a known online community or actor known for promoting misinformation, it is often just unique to that platform. For example, when Robert F. Kennedy Jr.'s Instagram was finally removed in February 2021, his accounts on Twitter, Facebook, and YouTube remained. Even his organization's accounts (Children's Health Defense) remained on all platforms, including Instagram. Not only do platforms need to move away from a content-level approach when it comes to known misinformation actors, but there needs to be a unified approach to deplatforming these kinds of accounts. Deplatforming problematic communities on mainstream platforms is an effective strategy [8], but moderation will always be seen as censorship in these digital communities unless you change the social norms of those communities [9]. It does not change the "hearts and minds" of the antivaccine or the vaccine hesitant.

But most importantly, the reason why moderation is not sufficient in curtailing vaccine misinformation and vaccine hesitancy is that it does not address the reasons why people have hesitancy in the first place. Vaccine misinformation ties itself to deep kernels of hard truths about healthcare that cannot be addressed overnight. People's distrust in pharmaceutical companies; healthcare inequities for women, gender minorities, and people of color; media and digital literacy worldwide; and the intertwining of policy and science are several factors that can be improved upon to diminish vaccine hesitancy and subvert vaccine misinformation beyond relying on content moderation.

This means we need to think about a national and a global initiative to not only address the vaccine "infodemic" but address the underlying factors that contribute to vaccine hesitancy. As academics and researchers who study phenomena at the intersection of people, data, and technology, it is critical for us to take a holistic approach to the national crisis we are in. Simply improving algorithmic moderation or providing a "fact check" will not adequately address vaccine misinformation. We need to

work together to continue teaching digital, media, and health literacy. We need to address the systemic issues affecting trust in healthcare, news outlets, and the academy. We need to treat vaccine hesitancy as a national emergency and collectively work together across disciplines for the betterment of the world.

References

- Salmon, D. A., Dudley, M. Z. et al. Vaccine hesitancy: causes, consequences, and a call to action. *Vaccine* 33 [2015], D66-D71.
- [2] Loomba, S., de Figueiredo, A. et al. Measuring the impact of GOVID-19 vaccine misinformation on vaccination intent in the UK and USA. Nature Human Behaviour 5, 3 (2021), 337–348.
- Hornsey, M. J., Harris, E. A. et al. The psychological roots of anti-vaccination attitudes: A 24-nation investigation. Health Psychology 37, 4 (2018), 307-315.
- [4] Koltai, K. Human values and scientific controversies: Studying vaccine information behavior on social networking sites. Doctoral dissertation. University of Texas at Austin, Texas ScholarWorks UT Electronic Theses and Dissertations, 2020.
- [5] Vosoughi, S., Roy, D. et al. The spread of true and false news online. Science 359, 6380 (2018), 1146–1151.
- [6] Chancellor, S., Pater, J. et al. #thyghgapp: Instagram content moderation and lexical variation in Pro-Eating disorder communities. In Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing. ACM, New York, 2016, 1201–1213.
- [7] Moran, R. E., Koltai, K., Grasso, I. et al. Content moderation avoidance strategies. The Virality Project. 2021; https://www.viralityproject.org/ rapid-response/content-moderation-avoidancestrategies-used-to-promote-vaccine-hesitantcontent
- [8] Chandrasekharan, E., Pavalanathan et al. You can't stay here: The efficacy of Reddit's 2015 ban examined through hate speech. Proceedings of ACM Human Computer Interaction 1, CSCW, Article 31 [Nov. 2017].
- [9] Gillespie, T. Custodians of the Internet: Platforms, content moderation, and the hidden decisions that shape social media. Yale University Press, 2018.

Biographies

Dr. Kolina Koltai is a postdoctoral fellow at the Center for an Informed Public at the University of Washington. Her research focuses on the anti-vaccine's community use of socio-technical systems to find, share, and assess vaccine misinformation. She received her Ph.D. in 2020 in information studies from the University of Texas at Austin.

Dr. Rachel E. Moran is a postdoctoral fellow at the Center for an Informed Public at the University of Washington. Moran received her doctoral degree in 2020 from the Annenberg School for Communication and Journalism at the University of Southern California. Her research explores the role of trust in digital information environments and is particularly concerned with how trust is implicated in the spread of misinformation and disinformation.

Izzi Grasso is a first year Ph.D. student at the Information School from the University of Washington. Her research interests include exploring misinformation regarding sexual health and sexual violence online as well as understanding how different communities theorize about content moderation and algorithmic harm.

Copyright is held by the owner/author(s).
Publication rights licensed to ACM.
1528-4972/21/12 \$15.00