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Exploring Distrust in the Wait and See: Lessons for Vaccine Communication

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Abstract

We conducted in-depth interviews with survey respondents who were distrusting of government authorities and/or communications, and also undecided about accepting the COVID-19 vaccine. Our sample was racially and ethnically diverse, mostly lower income without a college degree. Participants were concerned about their own health and cared about public health, but expressed mistrust in the government and the media. They generally felt ignored by public and institutional systems and expressed a desire to be listened to. These attitudes all influenced lack of confidence in the vaccine. We identify specific opportunities for intervention and communication in vaccine promotion. We propose longer-term solutions for improving trust, which is essential for the effective delivery of future health interventions.

Keywords

COVID-19, vaccine, hesitant, "wait and see", trust, attitudes, beliefs

Introduction

With COVID-19 continuing to spread throughout the United States, greater vaccine coverage remains a priority as large numbers of people continue to avoid vaccination

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and newer more contagious variants emerge. Although the partially or unvaccinated accounted for nearly all COVID deaths by September 2021, still only around half of eligible Americans had taken the vaccine by that time.

Several factors affect COVID vaccine uptake in populations. Structural factors include geographic access, economic access, racism, and health literacy. Cultural and behavioral factors include politization, whereby partisanship became strongly associated with opposing COVID mitigation and vaccination (Weisel, 2021). Leading up to the arrival of SARS-CoV-2 in early 2020, public health was increasingly becoming polarized. This was especially true for childhood vaccination. Around 2015, anti-vaccine groups began to effectively engage with coalitions, political action committees, and build a network of conservative politicians, mostly Republican (Haelle, 2021). The pandemic intensified this politicization, which became even more distorted during a particularly polarizing election year (Gollust et al., 2020). News coverage during this time was also found to be polarized and politicized, fueling the intensity of existing political passions (Hart et al., 2020).

Throughout the pandemic, those strongly opposed to the COVID-19 vaccine have disproportionally identified as Republican. The more cautious "wait and see" population, by contrast, has been found to be more racially, ethnically, and politically diverse (Hamel et al., 2021; Rusoja & Thomas, 2021; Tram et al., 2021).

The "Wait and See"

Before and during COVID-19 vaccine distribution, many research teams, including ours, consistently identified a large segment of the population that refused the vaccine but were open to changing their minds in the future.

Kaiser Family Foundation (KFF) research from August 2021 showed that those who "will definitely not get a COVID-19 vaccine," were more likely to be white (65%), than the "wait and see" group (50%). Black and Hispanic individuals were more likely than whites to identify as "wait and see," than "definitely not." Throughout the pandemic, the "wait and see" population remained more evenly divided racially, ethnically and politically than "definitely not" respondents (Hamel et al., 2021). Those with less education are also more likely than those with college or professional degrees to be in the "wait and see" group (Piltch-Loeb et al., 2021).

Survey research conducted by Surgo Ventures during 2021 labeled this segment, "the Persuadable," while identifying a second group as the "System Distrusters." These two segments essentially comprised the two groups that had the most potential to go from unvaccinated to vaccinated (SurgoVentures, 2021).

The Distrustful

Vaccination decisions take place within a complex ecology of values, beliefs, norms and experiences (Collins-Dexter, 2020), and yet distrust in various forms has been found to be a consistent factor in hesitancy. Well before the COVID pandemic,

governmental and institutional distrust was identified as one of the most important factors influencing refusal of influenza, smallpox, human papillomavirus, polio, and other vaccines (Baumgaertner et al., 2018; Hornsey et al., 2020; Larson et al., 2014; Lee et al., 2016).

Research has connected distrust-related vaccine hesitancy to the suffering of entire populations such as the centuries of mistreatment of African-Americans, and this has been explored and discussed throughout the vaccine rollout (Bajaj & Stanford, 2021; Bogart et al., 2021). What has not been explored yet is the effect of individual-level experiences and mistreatment with the medical system and how that may influence unwillingness to accept a vaccine.

The goal of our research was to discover the fundamental values, concerns and sources of distrust among a diverse sample of Americans who remained unvaccinated for COVID-19, and to conceptualize framing and other communications designed to increase vaccine acceptance and uptake. We concluded our interviews by asking participants for recommendations on how to build trust in our medical and public health systems, with the hope that this may yield insights on how to communicate in ways that would resonate.

Because of the urgency of COVID vaccine distribution, our interview guide was informed by surveys and qualitative research that were ongoing or recently completed. KFF's COVID-19 Vaccine Monitor offered up-to-date data and trends in public opinion. Surveys by the African American Research Collaborative offered nationally representative samples across race and ethnicity that explored issues of access and attitudes related to COVID-19 vaccines.

Redefining "Hesitancy" and "Access"

This pandemic has revealed limitations to the description of the "vaccine-hesitant" (Ratzan et al., 2021). New categories, such as those described above, are intended to better capture the complex influences on an individual's risk/benefit analysis for vaccine decision-making. Focusing on elements of this ecosystem, such as trust in government, may yield a better understanding of how to build confidence in vaccination for those individuals who are still undecided about accepting COVID-19 vaccines.

This evolving understanding of the harm of broadly assigning hesitancy to the unvaccinated has also revealed the complexities of what it means to have "access" to vaccination. Beyond the logistical access to a site where vaccines are available, there are significant barriers that keep many excluded from these processes. Just as "hesitancy" was overdue for a reframing, access is similarly overdue for, as our participants shared with us, if an individual has been excluded from systems that provide consistent health and child care, workplace protections, income security, and culturally-relevant information, they then lack access to an ecosystem conducive for clear vaccine decision-making.

Methods

Thirty participants were recruited through a national online survey conducted exploring trust and distrust. We completed a rapid scoping literature review on definitions and measurements of trust and survey tools used. From the literature, we reviewed dimensions associated with an individual's trust in vaccines in general (including specific ones such as measles, mumps and rubella[MMR] and influenza), the COVID-19 vaccine specifically, and healthcare systems.

We extracted questions from validated questionnaires and then developed the survey screening tool consisting of 20 questions in four categories of "trust": generalized trust, trust in health services and vaccine systems, trust in vaccines in general, and trust in COVID-19 vaccines specifically. The screener survey was fielded nationally in February 2021. Participants who received the vaccine or answered that they were "very likely" to get it were excluded from the remainder of the survey. Participants among this sample of 200 who demonstrated high levels of distrust through their survey responses were recruited from this sample.

In our interviews ($n = 30$), we explored ideas about the pandemic, vaccine hesitancy, and government/health system distrust. We asked them why they were not vaccinated, what it might take to get them vaccinated (or why they changed their mind and got vaccinated), and what they think it would take to convince other like-minded people to get vaccinated. It was critical to establish our own trust with participants during the interviews and we did that by telling them that our overall research goal was to help achieve a health system that recognizes the needs and concerns of everyone.

Our first interviews began in late March 2021 when equitable access was of particular concern, in addition to hesitancy. These interviews occurred during pivotal months of the COVID-19 vaccine distribution effort in the US, and we identified some important themes that we believe can help future vaccine communications and other public health response campaigns. Participants had many clear recommendations for how to support more trustworthy systems of public health communication, healthcare, and policy.

Findings

The COVID-19 vaccination landscape evolved throughout the course of our study, as it continues to change today. Concerns about trust, however, remained consistent throughout the interviews. Several participants spoke about the vaccines in terms of their relationship to government. Others spoke of distrust in the media and other institutions, and the feeling of being coerced into a behavior they were not ready to adopt.

> "I don't want the government to force me to put something in my body that I don't want to."

Some participants reported to us that, while once "wait and see," they got vaccinated in the time that passed between taking the survey and being interviewed. For people who changed their mind, quality of life and convenience played important roles: entertainment, travel, and seeing relatives who insisted on vaccination.

> "We worried about the unknowns but changed our minds when my father-in-law said we had to be vaccinated if we want to visit. Also we heard vaccination is required for travel. So we got vaccinated."

Navigating a Challenging Information Environment

All participants described the difficulty of navigating the "infodemic," as some have called it (Solomon et al., 2020; Zarocostas, 2020). Participants described the information environment throughout the COVID-19 pandemic as confusing, anxiety provoking, and trust-eroding. Competition between federal, state, and local jurisdictions (e.g., NYC v. NY State), and spokespeople added to the chaos.

> "I'm in Arkansas. You had the governor of Tennessee doing a press conference like I'm not understanding what Arkansas is doing. I have truck drivers who are coming in and out of the state, and I'm putting them in quarantine for 14 days. It was madness."

A continual need to assess the trustworthiness of institutions and authorities made this even more difficult.

> "I believe the media is just trying to blow it out of proportion, like all the death rates I've been seeing stuff like that, it don't seem true to me."

This environment decreased trust in public health authorities and traditional media sources.

Perceptions of Equity and Class Distinctions

Privilege, class, and wealth came up frequently in our interviews. Participants with lower access to care and resources perceived the vaccine as reserved for the more privileged and financially stable since wealthy people can more easily pay for any necessary medical treatments due to the possible side effects of the vaccines.

> "Why aren't the rich people or the high class people taking this seriously. They're still travelling. But us people who are not wealthy like them, we're locked down."

When asked if he would change his position if his sports idol publicly promoted vaccination, one participant responded:

> "If something is wrong with it, if he gets sick, he's still got money to support himself, and I got to be here sick and not working, so no."

Several participants raised issues of racial equity and mistreatment. Some mentioned the Tuskegee syphilis study or the talcum powder lawsuits against Johnson & Johnson as a reason to question the trustworthiness of the vaccine, and others told stories of their own experiences of blatant racism and mistreatment by the medical system.

> "I told them I had a bad reaction to my medication; she proceeded to tell me that you're not having a reaction to it. And I said, "Ma'am, I know when I'm having a reaction to (something) I've never taken before." And she just repeatedly said, "Oh well you'll be okay…"

Pivotal Experiences With Healthcare Providers and Health Systems

Participants described their relationships with the healthcare system in detail, and many of these were intense. Some participants had one or more traumatic experiences. Others had chronic conditions or survived serious illness in the past. Most participants had relationships with a medical doctor, some strong and frequent and others more episodic. Some participants told us their doctor advised against getting the COVID-19 vaccine, while others said they had not asked their physician for advice. Participants without a consistent relationship with a provider were less inclined to feel reassured by a doctor's advice.

> "There is one doctor … I would absolutely listen to this man, hands down. … He said 'to be honest with you hon, I couldn't tell you one way or the other right now because I'm not sure which way I'm leaning.'"

Participant Recommendations for Building Trustworthy Institutions

Participants consistently acknowledged the absence of opportunities to ask questions and voice their concerns. Many recognized the need for better local resources to fill these gaps. When asked what they might like to see, we heard:

> "Asking people what they want, asking people what would make them feel more comfortable, getting people's opinions."

> "...a CDC or something in every state where everybody knows about where you could go."

Overall, participants expressed a clear desire to be respected, and for the system to be more accepting of them. This was especially true given the stressful conditions they were under during these interviews.

> "We're all in this together. They need to stop pointing fingers … at the people taking the vaccine, or not taking it."

Polling data to date show that those most unwilling to receive COVID-19 vaccines tend to be White, male, and Republican (Hamel et al., 2021), which may be a product of the increasingly hard-line identity politics discussed above. We spoke mostly to those who were still questioning their decision, which may be one reason politics was rarely mentioned our discussions. What did come through were strong recommendations that may be applied across political sentiments.

Recommendations for Communicating in a Politically Polarized Environment

Despite the challenges of convincing distrusting individuals to get vaccinated, we believe important guidance can be generated from our findings. These communications and policy recommendations are based on our interviews, and informed by other evidence-based recommendations for communicating to the "wait and see" population, for example, (Miller, 2021; Ratzan et al., 2021; Rusoja & Thomas, 2021; Schwarzinger & Luchini, 2021; SurgoVentures, 2021).

Empathy and Respectful Communications

Among the clearest recommendation based on our research is to demonstrate respect for the people you communicate with about the COVID-19 vaccine. Many of our participants have had higher than average contact with the medical system, and expressed disappointment in the lack of respect for their own medical literacy. Despite the fact that the "wait and see" group skews less educated, their knowledge of the medical system is often well above average.

As Opel et al. (2021), state, "First, lead with listening. Patients, particularly those from marginalized communities, desire health care interactions in which their experiences are heard and validated." Our political and media landscapes are replete with critical and disrespectful language targeted toward those who hold different political ideologies and viewpoints. Our participants reinforced the presumption that the landscape is more likely to change within an environment of respect than under conditions of vitriol. Despite the time and patience that may be required to do this, a long history of communication research bears out its efficacy.

Our participants frequently discussed situations where government or media representatives lied, withheld information, or delivered inconsistent messages. Participants often felt they were not getting the whole story, that government representatives were withholding information, editing information, and hiding information.

The one-way information management from the past century has not been adequately updated into a more open format. Interactivity occurs in social media, and

throughout the internet; however, government and public health agencies still have not figured out a way to build an integrative relationship with its citizens.

Our participants asked for communications to be transparent about the nuances of health problems related to COVID-19 and solutions to address them. Others wanted the unknowns in a rapidly evolving information environment to be clearly and consistently explored.

Using diverse messengers to frame health issues around acknowledgment of population needs, desires, and values will be more likely to resonate than the blanket directives, which have been consistently shown to be ineffective and even counterproductive.

Mandates and How to Communicate Them

Policies regarding mandating COVID-19 vaccines weighs ethical considerations for legally placing limits on personal freedom compared to the proportional nature of risk involved (Fleming, 2021). As mandates already accentuate attitudes of distrust, the loss of agency inherent in mandates should be acknowledged. Recognition and discussion by public officials of the seriousness of mandates, the evidence for using them, and the need for responsible policies, can help build back the institutional trust necessary to increase vaccine acceptance.

As mentioned above, some of our participants chose to get vaccinated after carefully considering their unvaccinated status as a barrier to returning to activities such as travel, school, and family visits. Explaining the science behind the mandate (necessary protection in congregate settings, less reliance on mask wearing, etc.) is key to conveying the policy as protective and not infringing on personal freedoms.

Communicators can and should deliver messages that emphasize why public health matters and how security in one area of health, that is, disease prevention, is interrelated with others, that is, economic or housing security.

Facts Over Exhortations

Our participants were clear: Don't lecture us, beg, plead, or tell us to get vaccinated. Research with Republicans opposed to the vaccine similarly concluded that people want "education, not indoctrination" (Miller, 2021) People dislike being told what to do and are more likely to react negatively when that happens. Officials should be cautious about telling people to "get vaccinated." Paid social media ad campaigns may consider emphasizing statistical and epidemiological data about vaccine effectiveness and the risks of remaining unvaccinated (i.e., the seriousness of new variants) without the "hard sell" exhortation at the end. Surgo Ventures' research also recommends elevating data on racial disparities in vaccination and in COVID morbidity.

Framing: Emphasize the Positive

For many reasons that relate to the framing and reporting of news, the preponderance of communication about the vaccine focuses on preventing illness. However, as one participant told us, there is an opportunity to focus on the various positive effects, beginning with the feeling of relief one feels upon receiving the vaccine. This participant described this as one of the "positive side effects" of vaccination, and told us her husband and father both experienced this. It impacted her decision to eventually get vaccinated. Some participants described the relief and sense of wellbeing they felt after changing their mind, even despite ongoing concerns for possible long-term side effects. Others described the pride they felt as an example for their family members and communities—especially while young children cannot be vaccinated yet and others remain vulnerable. Public officials, physicians and other communicators can emphasize these experiences of relief and community leadership that people feel after getting vaccinated when speaking to their constituents or patients.

Peer-to-Peer is Always Effective

Our interviews supported previous findings which emphasized the power of one-to-one, communications. Our research confirms that individual-level communication must be an important component to any large-scale strategy. While peer-to-peer is consistently shown to be the most effective vehicle for behavior change, hotlines with helpful resources for people with questions about the vaccines, for example, will be well-received. Federal government programs that go door-to-door are another example of potentially effective one-to-one communication. Similarly, many participants preferred to garner advice and guidance from individuals who have shared their life experience in the communities they live or networks they participate in. Social media played a positive role in these instances. Highlighting these social media "wins" could encourage positive use of these networks.

Physicians as Communication

Medical professionals are still the most trusted source for health information (Bogart et al., 2021; Busker, 2021). Our participants valued and were influenced by their physician's perspective on health and the COVID vaccine. Strategies that mobilize the power of physician-patient communication about COVID vaccination and facilitate high quality, consistent interactions (and availability of vaccines in office practices) would likely improve vaccine uptake among the currently hesitant. Reimbursement for information-giving, for example, could encourage physicians and other health intermediaries to spend more time in these roles. The federal governments' plan to better equip PCP's with vaccine doses and door-to-door operations is another policy consistent with this finding.

A Longer-term Policy Agenda

Looking ahead to the next global health crisis, it is critical to highlight public health policy and procedure in times of good health and not only during life-altering emergencies. When the U.S. Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and the Department of Health and Human Services (HHS) speak on a national platform, it should not appear to the public that these authorities "arrived from out of the blue." The following are policy recommendations informed by the research explored here:

Policymakers should seek opportunities to facilitate "feedback loops" between policy makers and the public, to forge long-term community investment. Communities can resource the work of local nonprofits, and implement systems change that support community members in assuming leadership positions at all levels of the public health field. The lack of meaningful diversity in public health at the leadership levels, is one factor that may have contributed to community refusal to accept the vaccine.

Policies that help medical professionals build stronger and deeper relationships with their patients could mitigate some of the barriers and frustrations our participants felt, such as with repeated concerns about receiving care for short-term or long-term side effects.

Strategies to rebuild the eroding trust our participants expressed, and to support physicians and community health workers in their efforts to foster trust, should center the vision that healthcare is about people, not profit. This may include moving toward the expansion and accessibility of the medical home model.

Public health and medical environments should implement mechanisms that require the consultation of patients, particularly those who have been shut out of affordable care, before new policies can be developed.

It is critical the health system become re-imagined beyond the status quo. This may involve using pharmacies, health centers, and clinics as sites for building trust in medical professionals and medical information while delivering vaccines and other interventions.

Diverse stakeholders should facilitate multisectoral commitment to trustworthy communications and transparency. Partnerships and policies need to ensure there is "whole of society" commitment to reinforcing the measures outlined above. For example, platforms that allow proliferation of misinformation and contribute to the chaotic information environment should be incentivized to find solutions to overcoming these communications issues.

Both private and public sector have a responsibility to align messaging and determine shared goals that do not pit public health against economic health. These precedents should encourage cooperation to deliver consistent communications and instill confidence in mitigating measures, including vaccination.

Conclusion

The pandemic has laid bare the failures of current public systems and infrastructure to meet the public's health and information needs. Participants described numerous

instances when systems and authorities failed them and recounted frustrating interactions encountering bureaucracy and obtaining government benefits. Many participants perceived that the media, politicians, medical professionals, and businesses do not consider their values or best interests. They expressed that these entities and institutions are driven by ratings, power, and money, and that their ulterior motives create a context in which the everyday citizen cannot expect a product—in this case the COVID-19 vaccines—to be fully vetted or truly represented. We hope our research findings and recommendations will be helpful to policymakers and representatives from institutions responsible for communicating the features and benefits of the vaccines—now and into the future.

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