Discourses of Distrust: How Lack of Trust in the U.S. Health-Care System Shaped COVID-19 Vaccine Hesitancy

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This article explores the relationships between the American health-care system, trust in institutions, and decision-making processes that have affected COVID-19 vaccine uptake. Findings are based on an analysis of a nationally representative sample of 137 individuals who participated in semi-structured qualitative interviews during the rollout of the first publicly available vaccine in the first quarter of 2021. The vast majority of respondents reported negative experiences with American health care that predated the pandemic, which generated distrust in medical institutions, including hospitals, private health insurance corporations, the pharmaceutical industry, and related government institutions. The article considers the impact of institutional distrust on attitudes about vaccine uptake. Responses fell along a spectrum from vaccine refusal to vaccine acceptance. Sentiment across categories revealed a high degree of hesitancy framed in terms of institutional distrust. The data reveal a complex landscape of beliefs and perceptions, illustrating widespread hesitancy and ambivalence among participants.

Keywords: trust, vaccine, vaccine hesitancy, COVID-19, public health, health care, health insurance, institutions, medical-industrial complex

The COVID-19 pandemic raises serious questions about how a health-care system that has historically left many uninsured and underinsured can manage a public health crisis. Interviews with participants in the American Voices Project (AVP), a nationally representative qualitative interview survey of Americans, revealed persistently high barriers to accessing high-quality affordable health care in the United States. Such barriers have engendered a sense of distrust in the U.S. health-care system and its associated institutions, including hospitals, private health insurance corporations, the pharmaceutical industry, and government institutions charged with regulating and delivering care. COVID-19 vaccination efforts in the

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United States and the responses to those efforts have demonstrated the lethal consequences of institutional distrust at a time when individuals are explicitly asked to place their confidence in public health guidance and medical interventions.

Even though much has been written about the formidable barriers to high-quality affordable health care in the United States, less is known about the relationship between these barriers and the decision-making processes surrounding COVID-19 vaccine uptake. Data from our sample reveal a long history of negative experiences with the American health-care system that predate the onset of the pandemic and are strongly correlated with institutional distrust and widespread skepticism of the COVID-19 vaccine. Such a correlation helps explain the high degree of hesitancy in our data, including among participants who stated that they would likely receive the vaccine. Further, our data show that pre-existing distrust in a wide range of health-care institutions was nearly universal and therefore pervasive across race, gender, class, and political affiliation. Thus, rather than lending evidence to a polarizing discourse that hinges on a pro- and anti-vax binary, the data reveal a complex landscape of beliefs and perceptions, illustrating widespread hesitancy and ambivalence among participants across various dispositions.

This article draws a through line between distrust in American institutions and COVID-19 vaccination beliefs and intentions. We present and discuss our findings in two phases. First, we explore participant interactions with the American health-care system, highlighting the sources and contours of distrust in the medical-industrial complex. The data indicate that negative experiences with American health-care institutions were well entrenched before the pandemic. Thus, we purposefully use the term distrust rather than mistrust because the former indicates a settled belief rather than generalized doubt (Jennings et al. 2021). Second, having mapped the pervasive sense of distrust in the very institutions that play the most critical roles in vaccine development and delivery, we then discuss our participants' decision-making processes as they weighed the risks and benefits of vaccination. In their interviews, each of the 137 participants in our sample described their feelings about the newly developed COVID-19 vaccine as well as their intentions regarding vaccination. Combining attitudinal and behavioral data led us to develop a vaccine disposition typology onto which each participant was mapped (see table 1). This typology ranges from pro- to anti-COVID-19 vaccine uptake dispositions and features several degrees of hesitancy between the two extremes.

To operationalize vaccine hesitancy for our typology we borrowed from the work of Bipin Adhikari, Phaik Yeong Cheah, and Lorenz von Seidlein (2022, 2), who define vaccine hesitancy as "a state of uncertainty in decision-making due to doubts about the benefits of vaccines, their safety and necessity; and is a transient stage where a candidate may weigh the risks versus benefits of more emotional aspects associated with vaccinations." Unlike other descriptions that portray hesitancy in static terms, this definition captures the processual and transient nature of vaccine decision-making that we observed in participants as they described negotiating a barrage of institutional messaging while feeling heightened social pressure.

By considering respondent attitudes in the context of vaccine intentions, we were able to conduct a nuanced appraisal of decision-making that captured widespread ambivalence that might have otherwise been obscured. In categorizing participants into our vaccination disposition typology, we also tracked the reasons participants gave for their hesitancy. The most frequently cited reasons included a non-specific general lack of trust, feeling that the development of the vaccine was rushed, concern over unforeseen side effects, too little information about the vaccine, and lack of concern about contracting COVID-19. With the exception of being unconcerned about contracting COVID-19, all reflect matters of institutional trust. Further, because many participants discussed multiple reasons, even those who claimed they were not concerned about contracting the virus also cited trust-related reasons (such as "I don't really trust the vaccine and because I don't think I'll get COVID anyway it's not worth the risk"). Thus, we find that in-

Table 1. Vaccination Typology with Definitions and Examples

Disposition	Definition	Sample Quotes from the Data
Pro-vax	Respondent had received the COVID-19 vaccine or planned to and did not express hesitancy	I have already been vaccinated, I had both my shots. I'm excited for it. I plan on getting it for sure. Yes, I'm excited. I think I'm like literally in the last eligibility group with that so I will get it when I can.
Pro-vax hesitant	Respondent leaned toward receiving the COVID-19 vaccine but expressed hesitancy	I'll take it. I'm just not excited about taking a shot that has a lot of things that your body's not supposed to have into it. I'm a little scared to get the vaccination. . . . I'ma take it though I'm just scared about it. I think I'll probably get the shot when it's available for me to get or when I can get it, just because I know it will most likely help me. I'm definitely cautious about it. . . .
Undecided hesitant	Respondent was undecided about receiving the COVID-19 vaccine and expressed hesitancy	My jury is out. . . . I just don't really trust it at this point; I'm not sure whether I would get it. It's tough. Because I'll admit, I'm mixed on the whole the vaccine, . . . part of me is like, trust the system and take it in, and part of me is like, I just don't know. I'm still torn myself. I have on one side both of my parents have successfully gotten both of their doses of the vaccine as health-care workers, and they're doing fine. And then, I know of several people . . . he got his second dose, and got . . . a nerve infection from it.
Anti-vax hesitant	Respondent leaned away from receiving the COVID-19 vaccine and expressed hesitancy	I'm not planning to get it until it's safe and secure. I don't know. I just don't recommend taking it. None of [my family members] are going to get it until there's more data out there to show that it's actually doing something.
Anti-vax	Respondent had not and will not receive the COVID-19 vaccine and did not express hesitancy	No, we are not touching that stuff. No, I will not get the vaccine. I've already heard of too many disasters getting it No, I am not getting the COVID—the COVID vaccine. I don't get the flu shot. I am very concerned about vaccinations in general.

Source: Authors' tabulations.

stitutional trust is salient to understanding COVID-19 vaccine hesitancy.

LITERATURE REVIEW

Our analysis builds on research on trust and vaccines that has explored the dynamics that might have influenced respondents' dispositions during the rollout of the first publicly available COVID-19 vaccine. Trust in individuals and institutions is central to the vaccine decision-making processes. Trust as a social phenomenon can be conceptualized as "a relationship that exists between individuals, as well as between individuals and a system, in which one party accepts a vulnerable position, assuming the best interests and competence of the other, in exchange for a reduction in decision complexity" (Verger and Dubé 2020, 991). This definition demonstrates that trust can be both interpersonal and institutional and typically involves a level of risk which must be negotiated by a trusting party. Interpersonal trust is said to exist between individuals when one or more parties becomes vulnerable by placing their faith in another in order to gain a possible advantage (Spadaro et al. 2020). For our purposes, we might consider a layperson who does not have the medical training needed to empirically evaluate the risks and benefits of a particular vaccine. By placing their trust in a medical professional's endorsement of a vaccine, a layperson benefits from reduced decision complexity but also risks falling victim to bad medical advice.

Institutional trust, defined as "the extent to which individuals accept and perceive institutions as benevolent, competent, reliable and responsible toward citizens," offers similar risks and rewards (Spadaro et al. 2020, 3). The American health-care system, in its capacity to provide lifesaving care, is a powerful locus where one might develop institutional trust. Yet such institutions may also deny or create barriers to access to care, provide care at an exorbitant cost to patients, or provide substandard care, all of which may undermine institutional trust. Therefore, determining the extent to which health-care institutions can be trusted as "benevolent, competent, reliable and responsible" may be fraught as individuals weigh the benefits and risks of their vulnerability to institutional power.

Despite the distinctions between the two forms, institutional trust is frequently enmeshed with interpersonal trust. Because institutions are ultimately composed of individuals, institutional trust is necessarily structured by the trustworthiness of individual actors (Blendon 2006). For example, Robert Blendon and John Benson (2022) cite a study indicating that the United States, when compared with peer nations, ranked near the bottom in trust in health-care institutions, with only 14 percent of Americans surveyed reporting that they trusted hospitals completely. Yet, in the same study, 84 percent of Americans reported that they trust their individual doctors completely. Here, high levels of interpersonal trust are constrained by what is ultimately an institutional project, illustrating the complex dynamics of trust as a multifaceted sociological phenomenon.

We also emphasize a temporal dimension of both interpersonal and institutional trust. In explicating trust within the interpersonal, dyadic context, Dmitry Khodyakov (2007, 126) writes that "the decision to trust another person is made in the present and is affected by the partner's reputation, which represents the past, and by the expectation of possible tangible and/or non-material rewards, which represents the future." Thus we expand our definition of trust to conceptualize it as a process of "constant imaginative anticipation of the reliability of the other party's actions" based on "the reputation of the partner and the actor, . . . the evaluation of current circumstances of action, . . . assumptions about the partner's actions, and . . . the belief in the honesty and morality of the other side" (Khodyakov 2007, 126). Such a conceptualization suggests that past experiences are instrumental in undermining or bolstering trust in both interpersonal and institutional contexts.

Similarly, Khodyakov (2007) distinguishes "thick" and "thin" as two variations of interpersonal trust. Thick interpersonal trust is defined as "the first type of trust people develop in their lives," which is necessary for both "developing an optimistic attitude towards others" and

making social interactions possible (120). By contrast, thin interpersonal trust involves "trusting members of out-groups" and is "riskier" than thick interpersonal trust because it hinges on forming "relationships with people whose real intentions may not be clear" (121). Accordingly, trustworthiness in the absence of previous relationships depends on two factors: "the image of intermediaries that the trustor relies on for obtaining information about trustees . . . and/or the trustworthiness of institutions that back up trustees" (122). To understand this point, one need only think about recommendations sought and given by trustworthy intermediaries for various service providers (legal counsel, mechanics, doctors, and so on). Thin interpersonal trust, then, depends significantly on the reputation of the trustee as well as that of the intermediary of trust (see Zucker 1986).

Beyond the interpersonal domain, scholarly inquiry into institutional trust should benefit contemporary society precisely because we heavily rely on the state and its institutions in our everyday lives. Further, as Geraint Parry (1976) explicates, the institutional trust held by an individual corresponds to the presumed efficacy of state institutions. Like the significance of the parties' reputations in building thin interpersonal trust, institutional trust "depends on [institutions'] perceived legitimacy, technical competence, and ability to perform assigned duties efficiently" (Khodyakov 2007, 123). As Khodyakov (2007, 123) argues, "it is the impersonal nature of institutions that makes creation of institutional trust so difficult, because it is more problematic to trust some abstract principles or anonymous others who do not express any feelings and emotions." One of the central goals of institutional trust, then, is to cultivate "voluntary deference to the decisions made by institutions and increase public compliance with existing [and we might add new] rules and regulations."

Researchers have shown that trust plays a crucial role in gaining public support for vaccines, but no consensus has been reached regarding how trust should be assessed, the specific components of trust that should be considered, and the relationships that warrant investigation (Jamison, Quinn, and Freimuth 2019; Larson et al. 2014). This lack of consensus is not exclusive to vaccine-related studies but instead mirrors the inherent complexities associated with understanding the concept of trust. Clearly, though, trust in vaccines depends on both confidence in the vaccines themselves as products and trust in the system that is responsible for their production and distribution (De Freitas, Damion, and Han-I 2021; Jamison, Quinn, and Freimuth 2019).

To better understand the relationship between trust and vaccines, scholars have constructed models that capture factors that influence vaccine beliefs and behaviors (see, for example, Wiysonge et al. 2022; Verger and Dubé 2020; Dubé and MacDonald 2016). For example, the 3C model—which identifies three critical factors in vaccine hesitancy—parses vaccine attitudes, intentions, and dispositions into the following categories: complacency, the degree to which the disease is perceived as low-risk or the vaccine is perceived as having low efficacy; convenience, when behavior may be affected by logistical barriers; and confidence, when decision-making is based on perceived efficacy and trustworthiness (see Verger and Dubé 2020; Dubé and MacDonald 2016; MacDonald 2015). The 3C model is sometimes expanded to the 5C model, adding calculation (when decision-making rests on weighing the risks and benefits of a given vaccine) and collective responsibility (when behavior is influenced by one's desire to contribute to the overall health of one's community) as important factors that influence vaccine beliefs and behaviors (Wiysonge et al. 2022; Betsch et al. 2018).

The 5C framework includes factors such as individual beliefs, social dynamics, and institutional constraints, which together demonstrate that vaccine dispositions, including vaccine hesitancy, are "complex and context specific, varying across time [and] place" (World Health Organization quoted in Betsch et al. 2018). In line with Khodyakov's notion of "trust as a process," Ed Pertwee, Clarissa Simas, and Heidi Larson (2022, 458) argue that vaccine hesitancy is "better conceived of as a decision-making process rather than a fixed set of beliefs." An individual's vaccine disposition

may change over time and shift in various contexts, so scholars emphasize that expressing concern about a vaccine is not the same as assuming an anti-vaccination stance (Pertwee, Simas, and Larson 2022; Betsch et al. 2018; Dubé et al. 2013). Moreover, focusing on the processual nature of vaccine dispositions allows researchers to better understand how "cultural, temporal, and spatial" factors influence vaccine hesitancy (MacDonald 2015).

General vaccine-hesitancy literature offers practical tools such as the 3C and 5C models as well as theoretical frameworks that have significantly enhanced our understanding of COVID-19–specific phenomena. Theories of interpersonal trust in vaccine uptake are of particular interest, given that data show that trust between a patient and an individual care provider (such as a personal physician) is highly correlated with COVID-19 vaccine uptake (Karpman et al. 2021). Further, data show that COVID-19 vaccine intentions are affected by institutional trust in American health-care systems where a lack of trust in any or all components of this system can result in hesitancy and diminished compliance with recommended health practices (Blendon and Benson 2022; Bagasra, Doan, and Allen 2021).

DATA AND METHODS

The data for this article are derived from the American Voices Project (AVP), which conducts in-depth interviews to offer a rich and comprehensive landscape of life across the United States. The AVP reflects a nationally representative sample of hundreds of American communities as well as a representative sample within each of the selected sites. The AVP used three-stage cluster sampling in which census tracts were selected by stratified sampling and captured key geographic areas as single-block groups were sampled within tracts to focus on well-defined communities. Tracts and block groups were then selected with a probability proportional to the poverty population to explore the everyday lives of low-income populations. Additionally, select middle- and high-income populations were sampled for comparison purposes and to capture an overview of American life.

Interviews reveal critical dimensions of everyday life, including aspects of family life, living situations, community, health, emotional well-being, cost of living, and income as well as political perceptions. The AVP includes a database of 1,613 transcribed interviews. The data used in this article stem from a subsample of respondents ($N = 198$) interviewed between January 2021 and March 2021 during the health wave of interviews in which the AVP adjusted its protocol to better capture health-related issues. These health wave months marked a critical moment in which COVID-19 vaccines were becoming available to the American public for the first time.[1]

To best capture participants' decision-making processes, we excluded participants from the health wave interviews ($N = 198$) when we were unable to discern their vaccine dispositions. Although some participants declined to answer questions about their vaccine dispositions, the majority of those excluded were interviewed using a protocol that did not include a specific question about vaccine attitudes or intentions. In some cases, we were able to include participants from this group if other areas of their interviews indicated clear dispositions. A total of sixty-one participants were excluded, leaving a vaccine subsample ($N = 137$) on which our analysis is based. Respondents were assigned pseudonyms and, to protect their identities, inconsequential details from interview excerpts have been omitted or changed.

The vaccine subsample yielded a representative participant pool with diversity across race, gender, income, age, and political affiliations (see table 2). The subsample mirrored critical health-related demographics. For example, respondents reported that they had either received at least one dose of the COVID-19 vaccine or planned to receive it when it became

1. Between December 2020 and March 2021, COVID-19 vaccines were becoming available to health-care workers, first responders, individuals in congregate settings, and the elderly in the United States (Mayo Clinic 2022).

Table 2. Demographics (*N* = 137)

	Number of Respondents	Percentage of Sample
Panel A. Race-Ethnicity		
Non-Hispanic white	79	57.66
Non-Hispanic black	30	21.90
Hispanic or Latinx of any race	12	8.76
Multiracial, Asian, or no data	16	11.68
Panel B. Gender		
Female	80	58.39
Male (or no data)	57	41.61
Panel C. Income category		
Low	66	48.18
Middle	39	28.47
High	15	10.95
No data	17	12.41
Panel D. Age		
Young adult: 18–33	48	35.04
Middle aged: 34–59	57	41.61
Older adult: 60+ (or no data)	32	23.36

Source: Authors' tabulations.

available at rates comparable to the national rate of 47 percent.[2] Likewise, our respondents relied on public health insurance programs at rates on par with national data; 18.25 percent of AVP respondents in our sample were Medicare recipients compared with 18.4 percent of the U.S. population as a whole (see table 3; Keisler-Starkey and Bunch 2021). The only substantive difference between our sample and national statistics was the percentage of respondents who relied on private employer-based health insurance, 29.2 percent relative to 54.3 percent on the national level (U.S. Census Bureau 2021a). Parity in public coverage rates indicate that the discrepancy in private coverage reflects classification rather than demographic differences. For confidentiality reasons, table cells containing fewer than eleven participants were collapsed into the Insured–Other category (see table 3). Doing so obscured subsets of participants whose insurance likely flowed from employer-based coverage. For example, young adults in our sample who stated that they were covered by a parent's health insurance plan were classified as Insured–Other even though such coverage almost always flows from a parent's employer-based private health insurance plan.

Data are drawn from participant interviews that were conducted by a diverse team of advanced degree holders as well as graduate students, college graduates, and undergraduates; all team members were selected through a highly competitive process and received additional intensive training in qualitative methods. Members of the team were also tasked with applying a basic codebook to the interviews using NVivo qualitative coding software. This codebook was generated by AVP leadership to flag broad themes related to health, including participant experiences with the health-care system, perceptions of the COVID-19 pandemic, and attitudes toward the newly developed COVID-19 vaccine.

2. In our sample, 47.45 percent of participants (surveyed between January 6 and March 24, 2021) reported they had received at least one dose of the COVID-19 vaccine or planned to receive their first dose when it became available. In March 2021, the U.S. Census reported that 47 percent of Americans had received at least one dose of the vaccine (U.S. Census Bureau 2021b).

Table 3. Health Insurance Coverage (*N* = 137)

	Number of Respondents	Percentage of Sample
Employer	40	29.20
Medicaid	29	21.17
Medicare	25	18.25
Insured – Other[a]	43	31.39
Uninsured (or no data)		

Source: Authors' tabulations.

[a] Insured – "Other" includes respondents who were insured by an unspecified program, were on a parent's insurance plan, purchased a subsidized private plan through the insurance exchange marketplace, used VA/TRICARE (for veterans and their dependents), were students with university-based insurance, purchased an unsubsidized private plan through the insurance exchange marketplace, were covered by a Medicaid-equivalent program funded through the state, or were covered by private insurance through the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA).

We reviewed the transcribed interviews and previously coded data, analyzing the content inductively while developing a unique codebook to identify and categorize emerging themes. In addition to providing insight into how respondents perceived and interacted with American health-care institutions broadly, qualitative coding led us to develop a vaccine typology that categorized participants into one of five vaccine dispositions. We were frequently able to determine a respondent's disposition based on the following interview question: "Some people are excited about the new COVID-19 vaccine, and others not so much. How about for you?" The open-ended nature of this question, crafted to avoid social desirability bias, frequently elicited statements of intent and captured hesitancy when it existed (for example, "I'm not really excited about it. I'll probably get it, but I'm worried about the side effects"). That said, we did not assume that a participant's answer to this question was dispositive. Because many participants discussed COVID-19 when responding to multiple questions, we relied on a holistic evaluation of a participant's entire interview to classify their disposition. To ensure intercoder reliability, we developed a vaccination typology with definitions and examples (see table 1). Although our data are rich and support a nuanced analysis, this article is limited to the extent that it relies on interviews that we did not conduct using an interview protocol that we did not create. As a result, we were unable to tease out additional complexity, clarify ambiguous points, or explore the details of participants' experiences more fully. Future or follow-up research should be conducted to corroborate our findings.

SETTING THE STAGE OF DISTRUST

We can better understand the dynamics that influenced and continue to animate COVID-19 vaccination hesitancy by situating such discourses against the backdrop of individuals' experiences and perceptions of the U.S. health-care system. In this section, we demonstrate how negative experiences with the system generated distrust in the very institutions that individuals were asked to entrust with their lives and the lives of their families.

At the time of their interviews, almost all of our study participants were enrolled in some form of institutional health-care coverage that generally fell into one of three categories: private employer-based coverage or public coverage through either Medicaid or Medicare (see table 3). Despite the diversity of health-care needs, access points, and types of insurance coverage, the vast majority of our participants expressed dissatisfaction with their experiences accessing health care. With the exception of respondents who enjoyed generous coverage through union benefits or who were covered by multiple policies, most individuals expressed frustration with various aspects of the health-care system. Respondents were exasperated by

high co-pays and coinsurance, hidden costs and surprise billing, and lack of coverage for vision and dental care. Further, many were underinsured and found it difficult to pay both monthly premiums and medical bills that were generally not covered due to high deductibles. Many of these frustrations were directed at private insurance companies; however, participants also expressed dissatisfaction with other institutions such as hospitals and pharmaceutical corporations. Respondents also directed their frustrations at the government more broadly, both as a provider of health coverage in the form of Medicare and Medicaid and as the entity responsible for regulating private health insurers and the pharmaceutical industry.

Although most participants were covered by health insurance, many were still forced to forgo, delay, or ration care. Underinsured participants were covered by policies with both high premiums and high deductibles where they made large monthly payments for services that they still could not afford. Jennifer, a young, low-income white woman, said this of her mother:

> She has not been to the doctor in a long time, because insurance is just too crazy. She has health insurance, so it's kind of for emergencies. So, she won't go to the doctor because it's just too expensive. It's just too expensive to go get a physical and do a [wellness] check. . . . But I know my mom was paying like $500 a month. And that was just for emergencies. . . . And it was kind of, it was more than our house payment. So, it's kind of ridiculous.

Similarly, Susan, a low-income black woman in her sixties, explained, "it's like we have insurance, but then I go to a doctor I have to pay a $400 deductible; $400, that's a whole week's pay. So it's hard to stay healthy. So you let a lot of things slide, probably that you shouldn't." Despite paying for services that exceed the cost of a house payment or a week's wages, Jennifer's mother and Susan forwent the services that would help them "stay healthy."

In the face of such challenges, participants made strategic calculations that included rationing care. For example, Jeff, a white man in his fifties, said:

> My disability check does not go very far, and so I have had times that I ran out of [medication] and had to make our rations, make what I had last until payday or until I get the check. With my current [care provider], who also [treats] my [condition], it's $300, but I can't afford $300. So, I had to stop taking that medication. [There's one specialty medication that I need to take or else I'll die]. Everything else is icing on the cake.

Jeff's remarks illustrate how negative experiences navigating health-care institutions, such as the Social Security Disability Insurance system, can generate feelings of distrust as individuals are forced to make difficult and life-compromising decisions about their health and well-being.

Although participants described positive interactions with individual medical professionals such as doctors and nurses, the hospitals and other facilities where they received care were often regarded as prioritizing profits over people. For example, when Tomás, a middle-income Hispanic man in his twenties, went to the emergency room for a serious injury, the institution's priorities felt clear: "I'm bleeding, and they're worried about me filling out some papers. I just took a deep breath, and I'm like, 'Man, they're more worried about money than my health.'" In addition to frustration with bureaucratic protocols, another thought loomed over him: "As I'm walking into the door, honest to God, I'm thinking, 'And I might have to pay this big bill.'"

Echoing Tomás, Bill, a white man in his sixties, clearly indicated his disdain for and distrust in health-care institutions:

> They're all on quotas for how many minutes they're going to spend with a patient. And really, it's the bean counters running the system now; it's really appalling. It seems that the first thing they do is a walletectomy, of course; they want to see your medical insurance card and your charge cards and whatnot. It seems like the system is geared towards extracting the maximum amount of money for

> the minimum amount of service, and really efficiently, so I'm not especially pleased with it. It's all about hiding the cost so you don't know how much you're paying or who's paying it. The whole insurance system is really very destructive in that regard: you don't know what things cost, you don't know what you're really going to pay.

Here, Bill frames health-care institutions as being intentionally exploitative ("extracting the maximum amount of money for the minimum amount of service") and opaque ("It's all about hiding the cost"). His comments also indicate that he sees both service institutions and insurance corporations as enmeshed where the provider "hid[es] the cost" as part of an "insurance system that is really very destructive."

Building on his earlier comments, Bill discussed his attitudes toward pharmaceutical companies, whom he viewed as "rip[ping] off" consumers. To illustrate his point, he discussed a lifesaving medication that was affordable until the patent was purchased by a pharmaceutical company: "The company bought the patents on them and jacked up the price that should not have been permitted; those executives should have been marched down to a parking lot and dealt with." This comment exemplifies the distrust in the pharmaceutical industry that punctuates our data, and, when read with his earlier comments, reveals how some respondents regard the American health-care system as an industrial complex in which myriad institutions work together to confuse, exploit, and swindle citizens.

When discussing their general health-care experiences and the COVID-19 pandemic, many individuals directed their frustrations at politicians and the government. The majority of respondents did not reference specific people or point to particular laws when discussing their frustrations but instead expressed a general distrust in politicians and the U.S. government more broadly. As Lisa, a young white woman, noted, "I personally just find it incredibly horrible that we are in the middle of a global pandemic, and there's still people who are—and by people I mean politicians who find it appropriate to say, 'Yeah, well, I mean, health care is a privilege, not a right,' . . . that's just more of a societal America [that] does an atrocious job with our health care."

Similarly, Barbara, a middle-aged white woman encountering difficulty enrolling in a public health-care program, felt that the government did not care about her or others: "You're on your own, like too bad, even if you are applying for like disability, they don't care, they do not care." Barbara's and Lisa's testimonies illustrate some ways in which participants attribute barriers to accessing health care to the lack of competency ("an atrocious job with our health care") and lack of concern ("they don't care") from the U.S. health-care system and the government more broadly.

Although participant dissatisfaction with health care was persistent and predated COVID-19, the general sense of institutional distrust became increasingly pronounced as respondents began discussing their experiences during the pandemic. A number of participants specifically linked their pre-existing institutional distrust with their assessment of the COVID-19 vaccine. The pharmaceutical companies, in their roles as manufacturers and distributors of the vaccine, and the government, in its roles of overseeing vaccine development and responding to the pandemic more broadly, were the two most frequently cited institutions by participants. For example, when asked about his vaccine intentions, Kyle, a white man in his forties, remarked, "I'm always skeptical of the companies that developed it and what they put out, because they're in the process of trying to make money typically. So, anyone that's doing something with a financial interest I'm like more skeptical of."

Here, Kyle links his pre-existing distrust in corporations ("anyone that's doing something with a financial interest") to his specific distrust in the pharmaceutical companies responsible for producing the COVID-19 vaccine. Like Kyle, George, a white man in his sixties, considered his general distrust in the pharmaceutical industry as he contemplated receiving the COVID-19 vaccine: "Well, I would say in the light of the circumstance I'll take it when I get a chance, but I'm not hugely excited about drug companies. I don't, I don't trust them. I don't trust them, but in light of what's going on, I

don't know what, what is the—what else should we do?"

In his interview, George later assessed the federal government's competence at managing the pandemic: "I mean right now obviously the United States is the worst country in the world when it comes to handling this thing." When we read these comments together, we can see how distrust in one institution (the pharmaceutical industry) can sometimes spill over to lack of trust in related institutions (the U.S. government). Further, George's statements highlight how vaccine dispositions are more nuanced and less predictable than one might assume. Indeed, even though George states a clear intention to receive the vaccine ("I'll take it when I get a chance"), his declaration is couched within comments that express his dissatisfaction, hesitancy, and lack of trust. Ultimately, his decision to be vaccinated does not depend on a positive assessment of the vaccine or the health-care institutions in charge of creating and disseminating it. Instead, it is informed by an overall sense of resignation ("What else should we do?"). Given George's apathy for and distrust in multiple health-care institutions, one could easily imagine a scenario in which he instead chose to refuse the vaccine. His decision-making process illustrates the phenomenon that we discuss in the following section. Like many of his peers in this study, participants who either received or planned to receive the COVID-19 vaccine often expressed hesitancy. Further, the data show that discourse across the hesitant spectrum was remarkably similar.

VACCINE DISCOURSE AND DECISION-MAKING IN THE AGE OF COVID-19

This section builds on the preceding discussion to further explore the impact of existing institutional distrust on COVID-19 dispositions using a novel vaccination typology (see table 1). Based on interview data that revealed their vaccine attitudes and behaviors, we assigned respondents to one of the following categories:

1. Pro-vax: Respondent had received the COVID-19 vaccine or planned to and did not express hesitancy.
2. Pro-vax hesitant: Respondent leaned toward receiving the COVID-19 vaccine but expressed hesitancy.
3. Undecided hesitant: Respondent was undecided about receiving the COVID-19 vaccine and expressed hesitancy.
4. Anti-vax hesitant: Respondent leaned away from receiving the COVID-19 vaccine and expressed hesitancy.
5. Anti-vax: Respondent had not and will not receive the COVID-19 vaccine and did not express hesitancy.

By mapping each participant onto this typology, we find that participant decision-making processes are nuanced and that attitudes overlap even between respondents with oppositional dispositions (see tables 1 and 4). Indeed, individuals of all vaccine dispositions expressed varying degrees of distrust in health-related institutions. First, we begin with a brief discussion of individuals who did not express hesitancy about receiving the vaccine ($N = 86$). We then contrast these dispositions with a large cohort of respondents ($N = 51$) who were vaccine hesitant. We end the section by outlining the tipping points that nudge hesitant respondents to adopt a pro-vax stance.

As noted, pro-vax respondents had either received or planned to receive the COVID-19 vaccine and did not express hesitancy. Despite a lack of hesitation, many participants in the pro-vax sample ($N = 66$) still considered the role of trust when discussing health-care institutions. This frequently came in the form of considering why others might opt out of vaccination. For example, Kayla, a middle-income white woman in her twenties, explained: "I'm excited about it. I'm like, give me a call, I'll take it. I am not going to be someone to refuse this. I trust science, like, yeah, it hasn't been researched that much yet, I don't know, I trust the scientists who are working on it like 100 percent." Here, Kayla acknowledged a lack of information about the vaccine ("it hasn't been researched that much yet"), which could be cause for concern. However, Kayla's personal trust in science as an institution eclipsed this potential risk. Notably, Kayla discussed institu-

Table 4. Vaccination Disposition (*N* = 137)

Vaccine Disposition	Number of Respondents	Percentage of Sample
Panel A. Detailed		
Pro-vax	66	48.18
Pro-vax hesitant	22	16.06
Undecided hesitant	11	8.03
Anti-vax hesitant	18	13.14
Anti-vax	20	14.60
Panel B. Committed versus hesitant		
Pro-vax	66	48.18
Hesitant (all categories)	51	37.23
Anti-vax	20	14.60

Source: Authors' tabulations.
Note: For definitions of vaccine dispositions, see table 1.

tional trust ("I trust science") as well as trust in individuals ("I trust the scientists"). Although she does not mention specific individuals, such as a scientist whom she knows personally, her trust in scientists as individuals evinces the role of trusted intermediaries who facilitate institutional trust.

Unsurprisingly, on the other end of the spectrum, anti-vax individuals expressed starkly different views of the COVID-19 vaccine. Of the five dispositional categories, anti-vax participants (*N* = 20) were the most likely to claim that COVID-19 is fake, overblown, or used to intentionally frighten Americans. Such attitudes rest on a fundamental distrust in the U.S. health-care system, signaling a strong relationship between trust in government institutions and vaccine disposition. For example, Gina, a low-income black woman in her sixties, said:

> I don't trust it. They came up with it too quick. . . . We don't even know enough about what COVID is and then you're going to take a vaccine for something you don't even know. They ain't explained it enough to me. First, I didn't believe that it was actually real. Some people died of it. You know that they say people died. I don't trust the COVID vaccine. I don't think they researched it enough. They come up with it too quick.

Gina's response illustrates how a lack of knowledge about the COVID-19 virus and the vaccine is linked to perceived inadequacies ("They came up with it too quick"), communication failures ("They ain't explained it enough to me"), and general untrustworthiness in the U.S. health-care system ("You know that they say people died of it. I don't trust the COVID vaccine").

Finally, although rare in our sample, the racialized nature of anti-vax sentiments among some participants is noteworthy. Unlike demonstrably false conspiracy theories, the history in the United States of state-sponsored and state-sanctioned medical abuse of women, poor people, and people of color is documented (Wilson et al. 2023; Delgado 2020; INCITE! 2016; Washington 2006). Several anti-vax participants linked their historically informed, pre-existing distrust in the U.S. health-care system to their present-day vaccination dispositions. As Lydia, a low-income black woman in her sixties, explained: "Because of my history, African American history. Vaccines in America and just health care, being used as experimental pretty much. I can't think of the word I want to say. But you know what I mean? I think about that, and they are very suspicious. . . . So, because we have a bad history in America, we still have a long way to go. I'm not interested in the vaccine."

Several participants specifically referred to

the Tuskegee Syphilis Study—when the federal government purposely withheld treatment for syphilis to study its progression in a sample of four hundred black men (Emanuel et al. 2008). James, a middle-income, multiracial man in his seventies, said this: "What really got to me though is that the [COVID-19 vaccine] experiment was after the syphilis experiment. So my whole thing is that this is the government. My whole thing is, well, shoot, they did this syphilis [experiment], and it was back again, they did it again to the same people, the group of people in Tuskegee."

Like other respondents, James gave additional reasons for his anti-vax stance, including feeling that the development of the vaccine was rushed and that it would be impossible to anticipate its long-term effects: "Here, they [developed and manufactured the vaccine] in eight damn months, and that bothers me. Not to say it can't be right, but the whole thing is you really don't know what the side effects are. . . . But like I said, they have no idea what the outcome is going to be down the line."

Not only does James attribute his anti-vax disposition to distrust in the U.S. government, he also expresses concern over hasty manufacturing and side effects that might emerge in time. Here, James articulates two of the most common refrains expressed by anti-vax participants and hesitant participants across the typological spectrum: that the vaccine was produced too quickly, and citizens lack the knowledge needed to make informed decisions.

Even though pro-vax and anti-vax respondents are diametrically opposed, both cohorts' decision-making processes hinged on the presence or absence of trust in the U.S. health-care system. Similarly, in the subsample of hesitant respondents ($N = 51$), pro-vax hesitant, undecided hesitant, and anti-vax hesitant individuals share similar trust-related reasons, or core beliefs, for their hesitancy. For these participants, the leading causes of hesitancy were not knowing enough about the vaccine to trust it and observing the seemingly rushed development of the vaccine.[3] That many COVID-19 vaccine-hesitant participants did not express concern over well-established vaccines (such as for influenza) highlights the value that respondents place on the additional data points that are available for products with established track records.

Hesitant individuals developed several strategies to manage their concerns about the COVID-19 vaccine, the most common being the wait-and-see approach articulated by participants in all three hesitant subgroups. This approach leaves open the possibility of being vaccinated at some future point after one is able to gather additional data about the vaccine's safety and efficacy. Wendy, a low-income black woman in her forties whom we classified as pro-vax hesitant, stated, "I mean, I'm glad we have something that's going to, that's trying to clear this up. I'm just kind of waiting to see the outcome." When the interviewer asked whether she would get the vaccine, she answered, "Debatable. It's in the air. Like I said, I just want to see the outcome."[4]

Similarly, Ken, a white man in his sixties classified as anti-vax hesitant, questioned the efficacy of the vaccine and explained that he and his family would forgo getting the vaccine "until there's more data":

> You still have to do the social distancing. You still have to keep wearing the mask. You can still pass it to somebody else. You can actually still get it because at least one person in the news has gotten it after being vaccinated. So, at this point in time, I don't see the pluses of getting it. And my whole family feels the same way. None of us are going to get it until there's more data out there to show that it's actually doing something.

Notably, Wendy and Ken fall on opposite sides of the hesitancy spectrum (classified as pro-vax hesitant and anti-vax hesitant, respectively), yet use the same wait-and-see strategy

3. The COVID-19 vaccine is part of a class of mRNA vaccines that have been the subject of scientific research for three decades (Verbeke et al. 2021).

4. Although these statements seem to position Wendy in the undecided hesitant category, statements made elsewhere in her interview led us to classify her as pro-vax hesitant.

in their vaccine decision-making process. That participants across the hesitancy spectrum frequently navigate uncertainty in similar ways makes clear that vaccine behaviors (that is, uptake and refusal) are mutable and subject to change.

As noted, we conceptualize vaccine hesitancy as a state of uncertainty in which an individual is actively engaged in weighing the risks and benefits of vaccination (Adhikari, Cheah, and Seidlein 2022). Thus, hesitancy is volatile and subject to outside influence. Our analysis reveals a number of factors that can nudge participants toward or against vaccine acceptance, creating pro-vax tipping points among hesitant respondents. As the extant literature would suggest, our data confirm that such tipping points emerge where trusted intermediaries have the opportunity to facilitate institutional trust. For example, Carmen, a Hispanic woman in her thirties, did not plan to receive the COVID-19 vaccine until an outreach worker visited her community to promote vaccination. Although Carmen remained uncommitted at the time of her interview, community outreach in the form of an intermediary shifted her disposition from anti-vax to undecided hesitant. She also indicated that, if the vaccine were easily accessible, she would be even more inclined to receive it. Thus, we should consider how the efficacy of trusted intermediaries is boosted when barriers to entry are lowered. Our data show that local clinics, pharmacies, and community centers acted as tipping point hubs for many respondents who would otherwise be more vaccine averse. Such microinstitutions appear to be effective because they offer easy vaccine access administered by trusted intermediaries (such as a local pharmacist) in familiar settings.

Frequently, individuals who attributed their hesitancy to lack of information about the vaccine noted that they wanted to do their own research before deciding. Although the concept of doing one's own research is often derided by those who assume that the vaccine hesitant will find information from dubious sources, participants often used a variety of credible sources, including seeking out media representing diverse and balanced perspectives and consulting medical professionals to whom they have access. As Melissa, a middle-income Asian American woman, noted:

> I'm feeling mostly optimistic about it. And yeah, I mean, at first, I was pessimistic but that was my misinformation, my misunderstanding. And I was until I came across in a news article about an MD PhD in Texas that was developing a low-cost vaccine, that got my attention because I realized that "Oh, wow. Okay, this vaccine is not really the product of operation warp speed as former President Trump tried to claim, or he did claim." This vaccine is seventeen, eighteen years in the making.

Many participants were concerned about the apparent speed at which the COVID-19 vaccine was developed, but Melissa used news media featuring a credentialed expert to educate herself on the development of the vaccine. In doing so, her pessimism shifted toward optimism as she began to lean toward receiving the vaccine.

DISCUSSION

This article demonstrates how negative valuations steeped in past experiences with, and perceptions of, the U.S. health-care system generated distrust in institutions that seek to control public health crises. Regardless of insurance status, the vast majority of participants in this study were dissatisfied with the American health-care system. Because they had experienced this dissatisfaction for much of their lives, their trust in the system was compromised well before COVID-19 reached the United States. In the early days of the pandemic, most individuals watched an already overburdened health-care system strain under the weight of an unanticipated and unprecedented public health crisis. Despite their diverse backgrounds and experiences, as the first wave of COVID-19 vaccines became publicly available, all of our respondents were faced with the same question. Would they place their trust in the U.S. health-care system and its medical interventions to protect themselves and their loved ones from the COVID-19 virus? Here, like virtually all other Americans, our participants engaged their everyday life circumstances, social

networks, past experiences, and available information to decide whether they would opt to receive the vaccine.

During the rollout of the first vaccine, institutional pressure to be vaccinated was high. Although many of our respondents expressed a clear desire to receive the vaccination ($N = 66$) the majority were more reserved, with most expressing hesitancy or outright refusal ($N = 71$). We found that participants' vaccine dispositions resulted from a decision-making process that was social, cultural, and temporal. From a temporal standpoint, respondents drew on their pre-pandemic experiences with the American health-care system to evaluate potential future outcomes. Their dispositions at the time of the interview also reflected an appraisal of cultural messages communicated through media as well as the social influence of people in their immediate and extended social networks.

Even though medical professionals may feel frustrated by anti-vax or vaccine-hesitant attitudes and beliefs, our data underscore the importance of considering how information flows, and scientific knowledge in particular, are experienced by a variety of communities. Although the data are clear that COVID-19 vaccines are safe, effective, and necessary to protect the health of communities, we should be mindful of the context in which vaccine hesitancy arises and acknowledge the pervasiveness of vaccine hesitancy. Whereas a handful of individuals' vaccine dispositions hinged on anecdotal information or dubious sources, these findings did not characterize the majority of participants' core beliefs that led to vaccine hesitancy or refusal. In our review of 137 respondents, we found that vaccine opposition and hesitancy were rarely capricious but rather the outcome of agentic behavior amid various institutional constraints, including lack of institutional trust.

Our research makes both methodological and theoretical contributions to the extant COVID-19 literature. Methodologically, much of what we know about vaccine hesitancy relies on a large body of quantitative and survey data about general vaccine hesitancy as well as COVID-19-vaccine–specific hesitancy. We recognize that these datasets are rich sources of information but contend that qualitative data allow for more nuanced analyses that better capture decision-making processes. Frequently, quantitative projects rely on binary choices (such as "Have you taken the COVID-19 vaccine?" Yes/No), whereas surveys typically require a respondent to choose from a predetermined list of options (for example, "Which of the following options best describes your attitude toward the vaccine?"). In both cases, a respondent's ability to give a full accounting of their perspective is limited. In contrast, qualitative projects allow respondents to express their experiences on their own terms, facilitating the detection of novel patterns that are otherwise obscured by quantitative methodology. This study moves beyond statistical trends to capture the discrete narratives and personal stories that shape worldviews.

Further, qualitative research on COVID-19 vaccine hesitancy typically relies on small sample sizes that are not generalizable. In contrast, our dataset is large and nationally representative and thus offers thorough insights into the American public's attitudes and perspectives related to the COVID-19 pandemic. As we detail in the data and methods section, respondent demographics in our sample tracked closely with national data. Demographic similarities allow for greater generalizability in service of scaling our research in ways that exceed the scope of most qualitative projects. Having a high-quality, scalable qualitative dataset is especially valuable for inferences to national phenomena. Because participants were interviewed in the months surrounding the rollout of the first publicly available COVID-19 vaccine, their experiences speak to a wide audience because all Americans were undergoing similar processes in which they were evaluating existing information and forming vaccine intentions.

On a theoretical level, our findings further complicate discourses of polarization that place a wedge between pro-vax and anti-vax individuals. Although we were unsurprised that our data revealed a diversity of opinions related to the COVID-19 vaccine, we did not expect to find heightened levels of hesitancy among individuals on both sides of pro- and anti-vax

equation. We found that participants who said that they would likely receive the vaccine expressed trust-related concerns that were remarkably similar to those expressed by respondents who said they would refuse or would likely refuse it. Indeed, pro-vax participants who were not hesitant about being vaccinated themselves validated the trust-related concerns their hesitant counterparts expressed. Hence, despite dominant media discourse that has framed vaccine dispositions as a fiercely pro- and anti-vax dichotomy, we found that most participants across all categories experienced similar decision-making processes. Relatedly, we found that participants in every category engaged in active, agentic decision-making processes rather than passively accepting institutional messaging. Thus, contrary to a simplistic narrative of a deeply divided nation, this study reveals the synergies and convergences in beliefs that point to widespread institutional distrust.

By drawing attention to vaccine hesitancy, we show that people's stances are often more complicated than the pro- and anti-vax dichotomy suggests. The empirical richness of our data helped us explore the reasons, doubts, and fears that undergird these attitudes, offering a nuanced understanding of the factors influencing vaccine decisions. By unpacking and adding complexity to these narratives, we shed light on the salience of trust in the American public's decision-making processes, including the relationship between pervasive barriers to high-quality affordable health care and vaccine hesitancy. Although we abjured making causal claims, our research documents the correlation between pre-existing distrust in American medical institutions and COVID-19 vaccine hesitancy that has both scholarly and real-world applications.

In examining the relationship between institutional trust and COVID-19 vaccine disposition, we were struck by the distribution of participants along demographic lines. We were surprised to find that each dispositional category was quite diverse. Although privacy constraints prevent us from disclosing the precise composition of each category within our vaccine typology, we find that all classifications include members of each racial, gender, income, and age demographic. This finding led us to conduct preliminary research on an additional variable—political affiliation—that was not part of our original research design. The scope of our research intentionally focuses on pre-pandemic distrust in health-care institutions rather than political affiliation as a corollary to COVID-19 vaccine disposition. Indeed, we find the former to be undertheorized relative to robust scholarly and media discourse centered on the relationship between political affiliation and vaccine disposition. Research on political affiliation generally concludes a negative correlation between Conservative or Republican identity and COVID-19 vaccine uptake (see, for example, Dolman et al. 2023; Albrecht 2022). Our observations about race, gender, class, and age diversity within vaccine typologies led us to question whether respondent data on political affiliation might differ from extant research that primarily relies on larger quantitative datasets.

A cursory analysis of the political affiliation of the participants in our sample produces findings that one might expect.[5] For example, the majority of those categorized as pro-vax are Democrats. Similarly, Democrats are less likely to be anti-vax than their Republican counterparts. Despite these findings, our data indicate that pre-existing distrust in medical institutions was nearly universal and thus transcends political affiliation. Although we do not refute studies that show that Democrats may be more trusting than Republicans in a variety of settings, our data document a shared experience that, by definition, crosses party lines. We also find it noteworthy that a substantive number of participants did not identify with a major party, signaling another form of ambivalence. Even though we find that the majority of Democrats were typed pro-vax, more than one-third were either vaccine hesitant or anti-vax. In contrast, more than one-third of Republicans

5. To protect respondent confidentiality, we excluded the number of participants of each political affiliation as it relates to their vaccine disposition. We did not include a table that illustrates our findings for the same reason.

were firmly pro-vax and fewer than one-third established themselves as anti-vax, figures that are respectively higher and lower than one might expect. Further—and perhaps most surprising—we find that anti-vax respondents are balanced across political affiliations. These findings point to the fact that hesitancy is widespread across the political spectrum in ways that may be paradoxical or unexpected. It is possible that this is due to sampling bias or a small sample size relative to most quantitative datasets. Nevertheless, we contend that these findings are intriguing and could prove to be fertile ground for additional research.

These conclusions make novel contributions to the relevant literature in that they demonstrate a through line between areas of study that remain balkanized in contemporary scholarly literature—namely the chronic, well-documented decades-long phenomenon of distrust in the U.S. health-care system and the onset of an unexpected and unprecedented pandemic. Finally, although COVID-19 vaccine literature discusses institutional trust, we find that it fails to adequately consider institutional distrust to be a condition already well entrenched at the onset of the pandemic. As a result, the relationship between the American health-care system, trust in American institutions, and decision-making processes vis-à-vis COVID-19 vaccine uptake remains undertheorized.

As health-care administrators and governmental institutions grapple with vaccine hesitancy, they should consider how their efforts either undermine or build trust. For example, top-down messaging from public health institutions often present complex and sometimes contradictory information that may confuse and overwhelm their audience and further undermine trust. When this happens, it is all too easy to link overwhelming feelings of confusion to extant feelings of distrust in the health-care system. If we accept the premise that trust in novel solutions is paramount to addressing public health crises, our data indicate that state actors and institutions must operate on a variety of levels to rebuild trust in a system that has failed and continues to fail the majority of Americans. This includes reconciling past medical injustices, removing barriers to accessing quality care, and restructuring institutions to make health care more affordable. Further, because many of our respondents described being influenced by social networks rather than institutional messaging, efforts toward rebuilding institutional trust must be prioritized.

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