Medical mistrust, discrimination, and COVID-19 vaccine behaviors among a national sample U.S. adults

Jennifer D. Allen a,*, Qiang Fu a, Shikhar Shrestha b, Kimberly H. Nguyen b, Thomas J. Stopka b, Adolfo Cuevas a, Laura Corlin b,c

a Department of Community Health, Tufts University, 574 Boston Ave, Medford, MA, 02155, USA
b Department of Public Health and Community Medicine, Tufts University School of Medicine, Boston, MA, USA
c Department of Civil and Environmental Engineering, Tufts University School of Engineering, 200 College Ave, Medford, MA, 02155, USA

ABSTRACT

Background: COVID-19 vaccine uptake has been suboptimal and disparities in uptake have exacerbated health inequities. It has been postulated that mistrust in the healthcare system and experiences of discrimination or unfair treatment in other settings may be barriers to uptake of the COVID-19 vaccine, although few studies to date have investigated medical mistrust and perceived discrimination together.

Method: We conducted a cross-sectional online survey between April 23-May 3, 2021, among a national sample of U.S. adults ages 18 years and older. We assessed receipt of and intention to be vaccinated for COVID-19 and associations with the validated Medical Mistrust Index and Everyday Discrimination Scale.

Results: 1449 individuals responded, of whom 70.2% either had ≥1 dose of COVID-19 vaccine or reported that they were ‘very’ or ‘somewhat’ likely to be vaccinated in the future. In bivariate analyses, vaccination status was significantly associated with age, race/ethnicity, education, income, employment, marital status, health insurance, and political party affiliation. In multivariable analyses comparing those who had ≥1 vaccine dose or were likely to get vaccinated in the future with those who had not had any vaccine doses or did not intend to be vaccinated, each additional point in the Medical Mistrust Index was independently associated with a 16% decrease in the odds of vaccination (adjusted odds ratio = 0.84; 95% confidence interval = 0.81, 0.86). Discriminatory experiences were not associated with vaccination behavior or intention in bivariate or multivariable analyses.

Conclusions: Medical mistrust is significantly associated with vaccination status and intentions. Increasing uptake of COVID-19 vaccines will likely require substantive efforts on the part of public health and healthcare officials to build trust with those who are not yet fully vaccinated. We recommend that these efforts focus on building the ‘trustworthiness’ of these entities, an approach that will require a paradigm shift away from a focus on correcting individual beliefs and knowledge, to acknowledging and addressing the root causes underlying mistrust.

1. Introduction

The COVID-19 pandemic has exerted an unprecedented toll on the social, psychological, and economic health of the nation. In December of 2020, the first COVID-19 vaccine became available to priority populations (i.e., healthcare workers, first responders, and long-term care residents) (U.S. Food & Drug Administration, 2020) and was available for those aged 16 years and above in April of 2021 (U.S. Food & Drug Administration, 2021b). With available prophylactic vaccines, there is the potential to manage viral transmission and move into an endemic phase of COVID-19. The Centers for Disease Prevention and Control tracks vaccination, defining “completion of the primary vaccination series,” as having received either 2 doses of the Pfizer-BioNtech vaccine (given 3–8 weeks apart), or 2 doses of the Moderna vaccine (given 4–8 weeks apart), or 1 dose of the Johnson & Johnson’s Janssen vaccine, or 2 doses of the Novavax vaccine. CDC considers those who have completed the primary series as well as a recommended booster to be “fully vaccinated.” As of October 19, 2022, 91% of the U.S. population aged 18
and over have had at least one COVID-19 vaccine dose, and 78% were considered to have completed the primary vaccine series (Centers for Disease Control and Prevention, 2022b). Only 53% had received at least one booster dose (Centers for Disease Control and Prevention, 2022b).

There is a rapidly expanding body of research that has documented factors associated with COVID-19 vaccine uptake (Allen et al., 2021; Baack et al., 2021; Fisher et al., 2021; Guidry et al., 2021; Head et al., 2020; Malik et al., 2020; Reiter & Katz, 2021). Studies and polls consistently find that those who are younger, have less than a college education, and those who are male, Republican, or evangelical are less likely to have been vaccinated against COVID-19 compared to their counterparts (Allen et al., 2021; Fisher et al., 2021; Khubchandani et al., 2021; Neely et al., 2022). A number of studies have also found that psychosocial and behavioral factors, including fears about the safety and efficacy of vaccines (Baack et al., 2021; Bendau et al., 2021; Kirzinger et al., 2021; Nguyen et al., 2022a, 2022b) and social norms (Agranov et al., 2021; Charura et al., 2022; Minaya et al., 2022; Morgan et al., 2022) are associated with willingness to be vaccinated. Polls and published studies have also consistently found that mistrust of vaccines (Bogart et al., 2022; Latkin et al., 2021), government (Latkin et al., 2021; Tran et al., 2021), and pharmaceutical companies (Latkin et al., 2021) are associated with COVID-19 vaccine hesitancy.

A related, but slightly different construct is that of “medical mistrust,” which is a multifaceted concept that includes mistrust at the interpersonal (e.g., healthcare providers) and institutional levels (e.g., healthcare systems). Defined as “the tendency to distrust medical systems and personnel believed to represent the dominant culture in a given society” (Benkert et al., 2019), medical mistrust is associated with poor satisfaction with healthcare, lower uptake of medical recommendations regarding health behaviors or treatments, reduced quality of life, and worse health outcomes (Benkert et al., 2019; Birkhauser et al., 2017). Understandably, given historical atrocities and ongoing mistreatment, much of the research on medical mistrust has focused on Black and Native populations (Benkert et al., 2019). However, there also is substantial evidence that other socially disadvantaged or minoritized groups have high levels of medical mistrust, including those with lower socioeconomic status (Shoff & Yang, 2012) and those who identify as lesbian, gay, bisexual, transgender, or queer or questioning (LGBTQ) (Brenick et al., 2017; Cahill et al., 2017). There is a growing body of literature that documents that medical mistrust is a major barrier to vaccination for many populations (Bogart et al., 2022; Carson et al., 2021; Charura et al., 2022; Minaya et al., 2022; Morgan et al., 2022; Zhang et al., 2021).

For socially marginalized groups, medical mistrust may be the result of discrimination, exploitation, or unfair treatment within healthcare settings. Discrimination in the context of healthcare may be directly or vicariously experienced and can result in concerns about the motives or competence of healthcare providers or the overall medical system (Benkert et al., 2019). For example, in the Tuskegee Syphilis Study conducted by the U.S. Public Health Service between 1932 and 1972, investigators knowingly deceived African American men about the purpose of the study and withheld effective treatment for syphilis when it became available (Schuman et al., 1955). While this event occurred decades ago, its effects continue to reverberate, impacting the perceived trustworthiness of providers and the healthcare system among African Americans. In this context, mistrust can be viewed as an “adaptive, self-protective” response to historical exploitation, even if it is not directly related to the Tuskegee Syphilis Study (Benkert et al., 2019). Concerns about the Tuskegee Syphilis Study have been described in several qualitative studies of COVID-19 vaccine acceptance among African Americans (Bajaj & Stanford, 2021; Balasuriya et al., 2021; Majee et al., 2022).

Less is known about the potential impact of day-to-day discrimination experienced in different settings (e.g., schools, work, by police) and contexts (e.g., being treated with lack of respect in stores) on COVID-19 vaccine uptake. Discrimination is defined as unfair or unjust treatment based on individual identities or characteristics, such as gender, race/ethnicity, age, sexual orientation, or disability (U.S. Equal Employment Opportunity Commission), and is an important social determinant of health and health behavior. In a recent commentary in the New England Journal of Medicine, Singh Bajaj and Cody Stanford (2021) caution that “discriminatory attitudes and practices are a major determinant of health behaviors” and they emphasize that contemporary experiences of everyday racism are important factors in vaccine refusal among African Americans (Bajaj & Stanford, 2021).

Given the pervasiveness of discrimination (Lee et al., 2019) and the potential impact on COVID-19 vaccination, additional research on these relationships is warranted.

Our goal was to examine relationships between COVID-19 vaccine uptake, medical mistrust, and experiences of discrimination outside of medical settings. This investigation is particularly timely given that groups that have experienced a disproportionate burden of COVID-19 incidence and mortality (e.g., Black, Indigenous, and people of color, or BIPOC communities, those with lower socioeconomic status) (Iyanda et al., 2022; Pathak et al., 2022), often report greater levels of medical mistrust and higher levels of discrimination. However, as noted above, we identified only a few studies that examined these relationships. The COVID-19 pandemic has been marked by an epidemic of police violence (Bunch, 2021; Njoku et al., 2021), attacks on Asians (Ta Park et al., 2022), and an escalation of other forms of discrimination (Daniels et al., 2021; Paul et al., 2022; Ta Park et al., 2022). Findings from this study can provide meaningful insights to inform the development of interventions that address potential root causes of vaccine hesitancy.

2. Method

2.1. Data source

We used data from the second wave of the Tufts University Equity in Health, Wealth and Civic Engagement Study (Stopka et al., 2022) conducted between April 23-May 3, 2021. Online surveys were fielded by Ipsos, a social science company. Ipsos uses a web-enabled panel (KnowledgePanel®), an online, probability-based panel designed to be representative of the U.S. population. The panel was first developed by Knowledge Networks®, an Ipsos company, in 1999, when random digit dialing approaches were employed. A decade later, in response to the growing number of cellphone-only households, Ipsos transitioned to address-based sampling to ensure a nationally representative sample (Macninis et al., 2018; Yeager et al., 2011).

After initial acceptance of the invitation to join the panel, respondents were asked to complete a short demographic survey (the Core Profile Survey); answers to this survey allow efficient panel sampling and weighting. Upon completing the Core Profile Survey, respondents became active panel members. All panel members were provided confidentiality protections. The survey was conducted in English and Spanish. We randomly selected 2107 potentially eligible respondents ≥18 years of age, with 20% oversampling of Hispanic and non-Hispanic Black participants. A total of 1449 respondents (69%) completed the survey. The median time to complete the survey was 15 min. Following survey completion, qualified respondents received a standard incentive
from Ipsos (the cash equivalent of $1) and were entered into a sweepstake to win prizes of up to $500. The study protocol was reviewed and approved by the Institutional Review Board at Tufts University, Medford, U.S.A. (protocol 00000428).

2.2. Measures

Our dependent variable (“vaccination status”) was assessed with the following questions: “Have you received a COVID-19 vaccine?” (yes/no/unsure). For those responding in the affirmative, we asked: “Did you or do you plan to receive all required doses?” Response categories included: “Yes, I received all required doses,” “Yes, I plan to receive all required doses,” and “No, I don’t plan to receive all required doses.” Among those who had not had any doses of the vaccine—or were unsure about having been vaccinated in the past—we asked: “How likely is it that you will get the vaccine when you are eligible?” (very likely/somewhat likely/not sure/somewhat unlikely/very unlikely). Due to strong secular trends toward increasing vaccination and to reduce the potential for associated bias (especially given the lack of wide availability during the data collection period), we created a variable called “COVID-19 vaccination status” which incorporates past vaccine behavior with future intentions, resulting in two categories: 1) received ≥1 COVID-19 vaccine doses or were “very” or “somewhat” likely to get vaccinated in the future, and 2) not received any COVID-19 vaccine doses– or were unsure if they had received a COVID-19 vaccine– or were “very” or “somewhat” unlikely to be vaccinated in the future, or were “unsure” about being vaccinated in the future.

2.3. Independent variables

Medical Mistrust: We used the validated Medical Mistrust Index developed by LaVeist and colleagues that includes seven items to assess perceptions about the trustworthiness of healthcare organizations (LaVeist et al., 2009). Sample items include: “Healthcare organizations have sometimes done harmful experiments on patients without their knowledge” and “Mistakes are common in healthcare organizations.” Responses are on a 5-point Likert scale from strongly disagree to strongly agree. An overall score is created by summing responses on Likert scales, with higher values reflecting greater medical mistrust (theoretical range 1–28). To see the complete set of questions, see Appendix.

Everyday Discrimination: We assessed experiences of discrimination using the validated Everyday Discrimination Scale, developed and validated by Williams and colleagues (Krieger et al., 2005; Taylor et al., 2004; Williams et al., 1997). Items ask respondents: “In your day-to-day life, how often do any of the following things happen to you?” with experiences such as “You are treated with less courtesy than other people,” “You are threatened or harassed,” and “People act as if they think you are not smart.” Respondents were asked to estimate the frequency of each of these experiences (never/less than once a year/a few times a year/a few times a month/at least once a week/almost every day). This score was recoded into a range of 1–35, with higher scores indicating more experiences of discrimination for ease of interpretation. To see the complete set of questions, see Appendix.

Socio-demographic Characteristics: We compiled data from the Ipsos Core Profile Survey on socio-demographic characteristics shown to be associated with COVID-19 vaccine behaviors based on the scientific literature and our prior research: gender (binary: men/women), age (continuous), race/ethnicity (categorical: Hispanic/non-Hispanic Black/non-Hispanic White/non-Hispanic, another race non-Hispanic), education (categorical: less than high school/high school/more than high school), annual household income (categorical: ≤$19,999/$20,000–$49,999/$50,000–$74,999/$75,000), employment status (binary: working/not working), marital status (binary: married/not married), religious affiliation (categorical: Catholic/Evangelical or Protestant/other religion/not affiliated), health insurance (binary: insured/not insured), political party affiliation (categorical: Democrat/Republican/Independent or other), and Metropolitan Statistical Area (MSA) status (categorical: urban/rural/suburban).

2.4. Analysis

To examine the structure and internal consistency of the Medical Mistrust Index and Everyday Discrimination Scale, we assessed Cronbach’s alpha values. Scale reliability was deemed acceptable if alpha was greater than 0.70 (Nunnally & Bernstein, 1994). We then evaluated bivariate associations between COVID-19 vaccination status, key independent variables (Medical Mistrust, Everyday Discrimination), and potential confounders. We used means, linearized standard errors (SE), and standard deviations (SD) to describe the distribution of continuous variables. Percentages were reported for categorical variables. To assess bivariate associations, Rao-Scott chi-squared tests were used for categorical variables and analysis of variance (ANOVA) was used for continuous variables (Hair et al., 2011; Hair Jr et al., 2021).

We used logistic regression to identify associations between Medical Mistrust (and separately Everyday Discrimination) and vaccination status. Unadjusted odds ratios (ORs) and adjusted ORs (AOR), as well as associated 95% confidence intervals (CI) were reported. After adjusting for covariates that were significantly associated with vaccination status in the bivariate analyses (age, race/ethnicity, education, income, employment status, marital status, health insurance, and party affiliation), independent variables that were not significant (p > 0.05; marital status and health insurance) were removed from the multivariable logistic regression model. The final model reflects key independent variables that remained significant at p < 0.05.

All analyses applied sampling weights based on the March 2020 supplement of the U.S. Census Bureau’s Current Population Survey (US Census Bureau, 2020) to approximate characteristics of the U.S. population. A total of 87 participants with missing values on dependent or independent variables were removed from the regression analysis. SAS v.14.2 was used to perform the analysis.

3. Results

3.1. Characteristics of study sample

The mean respondent age was 48 years (SE: 0.6). More than half of respondents (63.0%) self-identified as non-Hispanic White, over half (88.9%) had a high school education or higher, and about half (54.2%) had annual household incomes of $75,000 or more. The vast majority (91.3%) had health insurance. Nearly three-quarters of respondents (70.2%) reported that they had either had one or more doses of the COVID-19 vaccine or were very/somewhat likely to be vaccinated. Nearly a third (29.8%) reported that they did not intend to be vaccinated or were unsure. See Table 1.

3.2. Bivariate analysis

In bivariate analyses, vaccination status was significantly associated (p < 0.05) with age, race/ethnicity, education, income, employment status, marital status, health insurance, and political party affiliation. We did not observe statistically significant associations between vaccination and gender, religion, or MSA status at the p < 0.05 level. The missingsness proportion for different variables varied from 0.0% to 4%. See Table 1.

Overall, the mean score on the Medical Mistrust Index was 15.1 (SE: 0.2). The mean for the Everyday Discrimination Scale was 5.1 (SE: 0.2). Participants who had received ≥1 COVID-19 vaccine doses or were ‘very’ or ‘somewhat’ likely to be vaccinated in the future had significantly lower mean scores on the Medical Mistrust Index compared to those that had not received any vaccine doses or were ‘very’ or ‘somewhat’ unlikely to be vaccinated in the future or were unsure (13.4 vs 19.0, respectively). Mean scores on the Everyday Discrimination Scale
Table 1
Sample characteristics by COVID-19 vaccine behavior and intention, United States, April 23-May 3, 2021 (N = 1449) ±

| Characteristic | Total N (%) | Received ≥1 dose or intend to vaccinate | Not vaccinated or do not intend to vaccinate or unsure | p-value |
|----------------|-------------|----------------------------------------|-----------------------------------------------------|---------|
|                | (N = 1070)  | (N = 1070)  | (N = 371)                                              |         |
| **Gender**     |             |                                        |                                                     |         |
| Men            | 744 (48.4)  | 552 (49.0)                              | 185 (45.5)                                           | 0.35    |
| Women          | 705 (51.6)  | 518 (51.0)                              | 186 (54.5)                                           |         |
| **Age (years)**|             |                                        |                                                     | <0.01   |
| 18-24          | 149 (19.7)  | 95 (17.3)                               | 50 (23.7)                                            |         |
| 25-34          | 220 (16.1)  | 137 (14.5)                              | 82 (20.2)                                            |         |
| 35-49          | 205 (15.9)  | 133 (14.4)                              | 72 (19.9)                                            |         |
| 50-64          | 460 (27.7)  | 350 (28.8)                              | 108 (25.6)                                           |         |
| ≥65            | 415 (20.7)  | 355 (25.1)                              | 59 (10.6)                                            |         |
| **Race/Ethnicity** |         |                                        |                                                     | 0.03    |
| Hispanic       | 354 (16.6)  | 257 (16.5)                              | 94 (16.5)                                            |         |
| Non-Hispanic   | 687 (41.1)  | 484 (31.0)                              | 203 (33.5)                                           |         |
| Black          | 76 (8.7)    | 59 (10.4)                               | 17 (5.0)                                             |         |
| White          | 678 (63.0)  | 506 (62.0)                              | 167 (64.6)                                           |         |
| **Education**  |             |                                        |                                                     | <0.01   |
| Less than high school | 154 (11.2) | 96 (8.7)                               | 56 (17.0)                                            |         |
| High school/ GED | 412 (27.4) | 258 (21.5)                              | 152 (41.0)                                           |         |
| College or higher | 883 (61.5) | 716 (69.8)                              | 163 (42.1)                                           |         |
| **Employment** |             |                                        |                                                     | <0.01   |
| ≤$19,999       | 127 (8.9)   | 69 (5.6)                                | 57 (16.5)                                            |         |
| $20,000-$49,999| 316 (20.5)  | 207 (17.3)                              | 107 (28.2)                                           |         |
| $50,000-$74,999| 242 (15.9)  | 148 (17.0)                              | 80 (22.2)                                            |         |
| ≥$75,000       | 764 (54.2)  | 610 (59.9)                              | 149 (40.0)                                           |         |
| **Marital Status** |         |                                        |                                                     | 0.04    |
| Married        | 860 (56.5)  | 413 (41.1)                              | 172 (48.8)                                           |         |
| Not working    | 589 (34.5)  | 657 (58.9)                              | 199 (51.2)                                           |         |
| **Religion**   |             |                                        |                                                     | 0.09    |
| Catholic       | 389 (25.9)  | 310 (28.2)                              | 70 (20.4)                                            |         |
| Evangelical or Protestant | 536 (34.6) | 390 (32.6)                              | 145 (39.3)                                           |         |
| Other religion | 201 (15.0)  | 143 (14.6)                              | 58 (15.4)                                            |         |
| Unaffiliated   | 300 (24.5)  | 213 (24.5)                              | 87 (24.7)                                            |         |
| **Health Insurance** |     |                                        |                                                     | <0.01   |
| Insured        | 1279 (91.3)| 974 (94.8)                              | 300 (83.0)                                           |         |
| Not insured    | 118 (8.8)   | 57 (5.2)                                | 60 (17.0)                                            |         |
| **Party Affiliation** |     |                                        |                                                     | <0.01   |
| Republican     | 534 (42.1)  | 325 (33.5)                              | 206 (62.7)                                           |         |
| Democrat       | 850 (53.0)  | 710 (63.8)                              | 138 (30.1)                                           |         |
| Other          | 53 (4.0)    | 29 (2.7)                                | 24 (7.2)                                             |         |
| **Metropolitan Statistical Area** |     |                                        |                                                     | 0.15    |
| Urban          | 548 (33.7)| 418 (35.8)                              | 126 (29.0)                                           |         |
| Rural          | 205 (17.6)  | 146 (17.1)                              | 58 (18.4)                                            |         |
| Suburbs        | 605 (48.7)  | 506 (47.2)                              | 186 (52.6)                                           |         |
| **Medical Mistrust Index** |     |                                        |                                                     |         |
| Mean (linearized standard error) | 15.1 (0.2) | 13.4 (0.2)                              | 19.0 (0.4)                                           | <0.01   |
| **Everyday Discrimination Scale** |     |                                        |                                                     |         |
| Mean (linearized standard error) | 5.1 (0.2)  | 5.0 (0.2)                               | 5.2 (0.4)                                            | 0.62    |

Note: Standardized Cronbach alpha (Medical Mistrust Index) = 0.90, Standardized Cronbach alpha (Everyday Discrimination Scale) = 0.84.

± Sample weights are applied to be representative of U.S. population.
*N represents the unweighted sample size, % is weighted percent for the column variable.

a Includes those who had ≥1 COVID-19 vaccine doses or who were unsure if they had received a COVID-19 vaccine or were "very" or "somewhat" likely to get vaccinated in the future.

b Includes those who have not received any COVID-19 vaccine doses or were unsure if they had been vaccinated or were "very" or "somewhat" unlikely to be vaccinated in the future.

*p-value was derived from the Rao-Scott chi-square test.

were not significantly different between these groups (5.0 vs 5.2, respectively). See Table 1.

3.3. Multivariable analyses

The unadjusted odds ratios (OR) and adjusted ORs (AOR) are depicted in Table 2, comparing those who had ≥1 dose of the vaccine or were ‘very’ or ‘somewhat’ likely to do so in the future with those who had not received any vaccine doses or were ‘very’ or ‘somewhat’ unlikely to be vaccinated, or were unsure. In analyses adjusting for age, race/ethnicity, educational level, income, employment, and political party affiliation, each additional point increase in the Medical Mistrust Index was associated with a decreased odds of vaccination (AOR = 0.84; 95% CI = 0.81, 0.86). Scores on the Everyday Discrimination Scale were not associated with the odds of vaccination status (AOR = 1.02, 95% CI = 0.99, 1.05). We tested the potential interactions between race and the two primary independent variables in a separate multiple logistic regression model. Both interaction terms were not statistically significant (results not shown). The missingness rate in these analyses was 6%. See Table 2.

4. Discussion

COVID-19 vaccines are the most promising means to end the pandemic. However, despite the emergence of a new, more contagious COVID –19 variant (Omicron) and its latest strains (BA.4, BA.5) (Phan et al., 2022; Tegally et al., 2022), and warnings from healthcare providers about the burden on the healthcare system, a substantial proportion of the U.S. population are not fully vaccinated or boosted. Moreover, there has been little change in intentions to be vaccinated over time (Baack et al., 2021; Nguyen, Huang, et al., 2022); one study found that the proportion of people who remained reluctant to be vaccinated did not change significantly between April to August 2021, and mistrust of vaccines and the government remained the top reasons for non-vaccination (Baack et al., 2021).

We found that mistrust in the medical system was associated with a reduced likelihood of COVID-19 vaccination and intention to be

Table 2
Multiple logistic regression for COVID-19 vaccination status, medical mistrust, and perceived discrimination, United States, April 23-May 3, 2021, (N = 1362) ±

| Characteristic | Received ≥1 vaccine doses and are likely to be vaccinated in future vs. Unsure or do not intend to vaccinate | OR* | 95% CI** | AOR*** | 95% CI |
|----------------|--------------------------------------------------------------------------------------------------------|-----|---------|--------|--------|
| **Medical Mistrust Index** | Received ≥1 dose of the vaccine or who were unsure if they had received a COVID-19 vaccine or were “very” or “somewhat” likely to get vaccinated in the future. |     |         |        |        |
| Everyday Discrimination Scale |                                                                                                        | 0.83 | 0.80, 0.86 | 0.84   | 0.81, 0.86 |
| **Bold**: *p < 0.05. Adjusted for age, race/ethnicity, education, income, employment, party affiliation, and either Medical Mistrust Index or Everyday Discrimination. Medical status and health insurance were no longer significant in this model, so were dropped to obtain the most parsimonious model. ± Sample weights applied to be representative of the U.S. population. *OR: crude odds ratios. ** CI: confidence interval. ***AOR: Adjusted Odds Ratio. |
vaccinated. Specifically, each additional point in the Medical Mistrust Index was associated with a 16% lower odds of vaccination behavior or intent. As noted above, our findings regarding mistrust are generally consistent with polls and studies that document that mistrust of vaccines (Bogart et al., 2022; Latkin et al., 2021), government (Latkin et al., 2021; Tram et al., 2021), and pharmaceutical companies (Latkin et al., 2021) are related to vaccine hesitancy. However, with notable exceptions (Thompson et al., 2021) multi-item, validated measures of medical mistrust were not used in studies.

Nevertheless, contrary to our expectations, experiences of discrimination in other non-healthcare settings were not associated with vaccination behaviors. Our finding that unfair treatment and discrimination outside of the medical system was not significantly associated with COVID-19 vaccination status is not entirely consistent with the few other published studies in the U.S. of which we are aware. In an online survey of N = 2650 U.S. adults conducted in December of 2020, Savoia et al. examined experiences of discrimination across a variety of settings (work, school, by police, financial institutions, as well as healthcare) attributed to race, religion, gender, and sexual orientation (Savoia et al., 2021). They found that discrimination attributed to race across these settings was associated with COVID-19 vaccine hesitancy (OR = 1.21, 95% CI = 1.01–1.45), but discrimination attributed to age, gender, sexual orientation, or religion was not (Savoia et al., 2021). Another U.S. study of N = 1185 U.S. adults with MTurk accounts living in five New England states found that both perceived discrimination and medical mistrust indirectly mediated the relationship between race/ethnicity and receipt of the COVID-19 vaccine (Morgan et al., 2022). Finally, a study conducted N = 776 Black, Asian and Latinx individuals in the U.S. found that medical mistrust was associated with COVID-19 vaccine hesitancy (Minaya et al., 2022). Studies from outside the U.S. have also found that medical mistrust and discrimination impact COVID-19 vaccination (Charura et al., 2022; Zhang et al., 2021). For example, a study from the U.K. conducted among N = 633 individuals from ethnic minoritized groups found that racial/ethnic discrimination was associated with a four-fold decrease in odds of being vaccinated, and this effect was mediated by low trust in healthcare systems to ‘handle the pandemic’ (indirect effect: OR = 2.5, 95% CI = 1.1 to 5.4) (Paul et al., 2022). Inconsistencies between our findings and other studies may be due to different conceptual or operational definitions of discrimination (i.e., single items vs validated scales) (Williamson & Bigman, 2018), the settings in which it was assessed (e.g., workplace, schools, police, and/or healthcare), or the factors to which discrimination was attributed (i.e., race alone versus race and other individual characteristics).

Our study has limitations that we acknowledge. First, these data are cross-sectional, so we cannot draw causal inferences or rule out reciprocal causation between vaccination status and medical mistrust. Second, like many studies, our analysis examined the frequency of discrimination but did not include an examination of what aspect of one’s identity respondents attributed the discrimination. Third, while our sample was selected randomly from an Ipsos panel of U.S. adults, there is a potential for selection bias. Reassuringly, the weighted percentages of our sample by gender, age, race/ethnicity, marital status, and income were comparable to those of the 2019 U.S. Census Bureau’s Current Population Survey (US Census Bureau, 2020). However, caution should still be used when attempting to generalize findings. Finally, while we oversampled Black and Hispanic individuals, our stratified sample sizes for these racial/ethnic groups may have still been too small to provide sufficient statistical power to examine interactions with discrimination experiences in relation to vaccination.

Limitations notwithstanding, our study has several important implications. The first is that efforts to reach those who are uncertain or remain resistant to being vaccinated need to be sensitive to individuals’ concerns and past experiences with the healthcare system and with government. It is critical to generate a better understanding of these issues. For example, while the main drivers of mistrust for minoritized groups may be structural racism, drivers of mistrust among non-minoritized groups may be rooted in mistrust of government. Different approaches may be needed to address the most salient factors among different populations.

Historically, the public health approach to addressing medical mistrust has largely focused on changing attitudes about healthcare among those who have had negative experiences (Sullivan, 2020). For example, the CDC recommends training respected community leaders or trusted messengers to be “vaccine ambassadors,” who then disseminate accurate information about vaccines within their social networks and assist individuals to navigate healthcare or vaccine appointments (Centers for Disease Control and Prevention, 2022a; Quinn, 2020; Sullivan, 2020). However, these approaches do not seek to change institutions. An alternative approach would emphasize initiatives that increase the trustworthiness of public health and healthcare institutions (Sullivan, 2020) by addressing systemic bias and prejudice in these settings. Efforts focused on trustworthiness must start with listening to and acknowledging historical and contemporary harms and appreciating and addressing the social underlying determinants that give rise to mistrust (e.g., structural racism, political and power structures). Shifting the current paradigm—currently focused on individual choices, information dissemination, and mitigating mis/disinformation— to addressing root causes of mistrust and building trustworthiness may not only yield benefits in terms of COVID-19 vaccine uptake but could have ‘spillover effects’ to other areas that could improve the health of populations that experience inequities.

Mistrust can both give rise to and be a result of unclear and inconsistent health messaging, which has been a major source of public confusion and skepticism during the COVID-19 pandemic (Van Scoy et al., 2021). Shifting recommendations (e.g., social distancing), reversing course (e.g., mask-wearing early in the pandemic), lack of transparency regarding reporting of COVID-19 vaccine/treatment clinical trial data (Kapp et al., 2022), and the promulgation of inaccurate and dangerous information about COVID-19 treatments, have all contributed to mistrust. While there are calls to improve “vaccine literacy” (i.e., changing individuals’ ability to access, understand, and critically evaluate vaccine information)- again, focused on individuals—there is also a need to acknowledge and remedy serious missteps made by public health and healthcare authorities in communicating complex COVID-19 information. It is critically important that communication strategies (especially those used during times of crisis) be sensitive to the concerns and values of diverse audiences, that messages be delivered by trusted authorities (who may differ for each audience), and that information is disseminated through preferred modes of communication for specific audiences. Understanding how medical mistrust differs across populations (e.g., mistrust of motives vs mistrust of competence) will also be important for these efforts. To that end, there is ample evidence that involving trusted community leaders in the design of health campaigns can be instrumental in building trust (Hyland-Wood et al., 2021). Moreover, unlike shorter-term approaches (e.g., community outreach, social media campaigns), meaningful investment in community infrastructures and mutually-beneficial community partnerships may bring about longer-term changes that can facilitate improvements in health inequities that preceded (and were exacerbated by) the COVID-19 pandemic (Ojikutu et al., 2021).

These issues will be particularly important as we enter the next phase of the pandemic. Although the first booster vaccines became available for all adults in the U.S. by November 2021 (U.S. Food & Drug Administration, 2021a), and a new bivalent COVID-19 booster has recently been approved (U.S. Food & Drug Administration, 2022b), addressing the underlying reasons for medical mistrust will not only help to promote uptake of the currently available COVID-19 vaccines, but could also lay the foundation for future vaccine campaigns.
Funding sources

This research was supported by the Tufts University Office of the Vice Provost for Research, Equity in Health, Wealth, and Civic Engagement initiative (Allen, Stopka), the Tufts Clinical and NIH Tufts Translational Science Institute (UL1TR002544), the COVID-19 Rapid Response Seed Funding Program (Allen, Corlin, Stopka). Laura Corlin was supported by Eunice Kennedy Shriver National Institute of Child Health and Human Development (K12HD092535).

Conflicts of interest

All authors declare that they have no conflicts of interest.

Human rights

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All procedures were approved by the Tufts University Social, Behavioral & Educational Research Institutional Review Board.

Consent

Informed consent was obtained from all individual participants included in the study.

Welfare of animals

This article does not involve animals.

Transparency statements

(1) this study does not meet the requirements of a clinical trial; (2) the analysis plan was not formally pre-registered; (3) de-identified data from this study are not available in a public archive. De-identified data from this study will be made available (as allowable according to institutional IRB standards) by emailing the corresponding author; (4) analytic code is available on reasonable request from the corresponding author; (5) materials used to conduct the study are not publicly available but may be made available by request by emailing the corresponding author.

Financial interests

The authors declare they have no actual or potential competing financial interests.

Data sharing statement

Analytic code is available on reasonable request from the corresponding author.

Acknowledgements

We thank all the participants of the study.

Author statement

All authors made substantial contributions to the design of the study, interpretation of data, and have drafted the work or substantively revised it. All authors have approved the submitted version and agree both to be personally accountable for the author’s own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. None of the authors report conflicts of interest. The data that support the findings of this study are available upon reasonable request from the corresponding author, JA.

Data availability

Data will be made available on request.

References

Agranov, M., Elliott, M., & Ortoleva, P. (2021). The importance of social norms against strategic effects: The case of covid-19 vaccine uptake. Economics Letters, 206, Article 109979, 34230727.

Allen, J. D., Feng, W., Corlin, L., Porteny, T., Acevedo, A., Schildkraut, D., et al. (2021). Why are some people reluctant to be vaccinated for COVID-19? A cross-sectional survey among U.S. Adults in May-June 2020. Preventive Medicine Reports, 24, Article 101494. https://doi.org/10.1016/j.pmedr.2021.101494

Baack, B. N., Abad, N., Yankey, D., Kahn, K. E., Razzaghi, H., Brookmeyer, K., et al. (2021). COVID-19 vaccination coverage and intent among adults aged 18-59 Years - United States, March-May 2021. MMWR Morbidity and Mortality Weekly Report, 70, 928-933. https://doi.org/10.15585/mmwr.mm7025e2

Bajaj, S. S., & Stanford, F. C. (2021). Beyond tuskegee — vaccine distrust and everyday racism. New England Journal of Medicine, 384, e12. https://doi.org/10.1056/NEJMp2035827

Balasuriya, L., Santailli, A., Morone, J., Ainooson, J., Roy, B., Njoku, A., et al. (2021). COVID-19 vaccine acceptance and access among black and Latinx communities. JAMA Network Open, 4, Article e2128575. https://doi.org/10.1001/jamanetworkopen.2021.28575

Bendau, A., Plag, J., Petzold, M. B., & Strohle, A. (2021). COVID-19 vaccine hesitancy and related fears and anxiety. International Immunopharmacology, 97, Article 107724. https://doi.org/10.1016/j.intimp.2021.107724

Benkert, R., Cuervas, A., Thompson, H. S., Dove-Meadows, E., & Knuckles, D. (2019). Ubiquitous yet unclear: A systematic review of medical mistrust. Behavioral Medicine, 45, 86-101. https://doi.org/10.1080/08964289.2019.1588220
Birkhauser, J., Gaab, J., Kossovsy, J., Hasler, S., Krummenacher, P., Werner, C., et al. (2017). Trust in the health care professional and health outcome: A meta-analysis. Journal of Health Care, 12, Article e1579088. https://doi.org/10.1719/journal.pone.0157908

Bogart, L. M., Dong, L., Gandhi, P., Klein, D. J., Smith, T. L., Ryan, S., et al. (2022). COVID-19 vaccine intentions and mistrust in a national sample of black Americans. Journal of the National Medical Association, 6(113), 599–611. https://doi.org/10.1011/jama.2021.599611

Brenic, A., Romano, K., Kegler, C., & Eaton, L. A. (2017). Understanding the influence of stigma and medical mistrust on engagement in routine healthcare among black women who have sex with women. LGBT Health, 4, 4–10. https://doi.org/10.1089/lgbt.2016.0088

Bunch, L. (2021). A tale of two crises: Addressing covid-19 vaccine hesitancy as promoting racial justice. JHEC Forum, 33, 143–154. https://doi.org/10.1077/jhec.01705902

Butler, J. Z., Carson, M., Rios-Fetchko, F., Vazag, R., Cabrera, A., Gallegos-Castillo, A., et al. (2022). COVID-19 vaccination readiness among multiple racial and ethnic groups in the san francisco bay area: A qualitative analysis. PLoS One, 17, Article e0266937. https://doi.org/10.1371/journal.pone.0266937

Cahill, S., Taylor, S. W., Elsesser, S. A., Mena, L., Hickson, D., & Mayer, K. H. (2017). Trust in the health care professional and health outcome: A meta-analysis. Journal of the National Medical Association, 6, 1707–1704. https://doi.org/10.1011/jama.2021.17074

Kapp, P., Esmail, L., Gnon, L., Rauvat, P., & Boutron, I. (2022). Transparency and reporting characteristics of COVID-19 randomized controlled trials. medRxiv, Article 22073075. https://doi.org/10.1101/22073075

Khubchandani, J., Sharma, S., Price, J. H., Wiblishauser, M. J., Sharma, M., & Webb, F. J. (2021). COVID-19 vaccination hesitancy in the United States: A rapid national assessment. Journal of Community Health, 46, 270–277. https://doi.org/10.1007/s10900-020-00908-4

Krieger, N., Smith, K., Naishadham, D., Hartman, C., & Barbeau, E. (2005). Medical mistrust, COVID-19 vaccines, and interest to vaccinate in racial-ethnic minorities (Vol. 12). Basel: Behav Sci. Article 10.3390/bs1206186.

Majee, W., Anakewe, A., Onyeaka, K., & Harvey, I. S. (2022). COVID-19 vaccine hesitancy among African American adults using qualitative data. Journal of Racial and Ethnic Health Disparities, 1–13. https://doi.org/10.1007/s40615-021-01337-z

Malik, A. A., McFadden, S. M., Elbarake, J., & Omer, S. B. (2020). Determinants of COVID-19 vaccine acceptance in the US. EClinicalMedicine, 26, Article 100495. https://doi.org/10.1016/j.eclinm.2020.100495

Nguyen, K. H., Huang, J., Mansfield, K., Corlin, L., & Allen, J. D. (2022). COVID-19 vaccination coverage, behaviors, and intentions among adults with previous diagnosis, United States. Emerging Infectious Diseases, 28, 631–638. https://doi.org/10.3203/2021.187. https://doi.org/10.1007/s11606-021-07171-z

Njoku, A., Ahmed, Y., & Boddie, B. (2021). Police brutality against Blacks in the United States and ensuing protests: Implications for social distancing and Black health during COVID-19. Journal of Health and Social Behavior, 31, 262–270.

Ojikutu, B. O., Stephenson, K. E., Mayer, K. H., & Emmons, K. M. (2021). Building trust in COVID-19 vaccines and beyond through Authentic community investment. American Journal of Public Health, 111, 366–368. https://doi.org/10.2105/ajph.2020.02954

Ojikutu, B. O., Stephenson, K. E., Mayer, K. H., & Emmons, K. M. (2021). Building trust in COVID-19 vaccines and beyond through Authentic community investment. American Journal of Public Health, 111, 366–368. https://doi.org/10.2105/ajph.2020.02954

Sullivan, L. S. (2020). Trust, risk, and race in American medicine. Journal of Public Health, 111, 366–368. https://doi.org/10.2105/ajph.2020.02954

Stopka, T. J., Feng, W., Corlin, L., King, E., Mistry, J., Mansfield, W., et al. (2022). COVID-19 vaccination readiness among multiple racial and ethnic groups in the san francisco Bay area: A qualitative analysis. PLoS One, 17, Article e0266937. https://doi.org/10.1371/journal.pone.0266937

Shoff, C., & Yang, T. C. (2012). Untangling the associations among distrust, race, and medical mistrust, and mattering in ethnically diverse communities. Journal of Racial and Ethnic Health Disparities, 1–8. https://doi.org/10.1007/s40615-022-01106-0

Tuskegee study.
Ta Park, V. M., Dougan, M. M., Meyer, O. L., Nam, B., Tsuang, M., Park, L. G., et al. (2022). Discrimination experiences during COVID-19 among a national, multi-lingual, community-based sample of Asian Americans and pacific islanders: COMPASS findings. *International Journal of Environmental Research and Public Health, 19.* https://doi.org/10.3390/ijerph19020924 PMCID: PMC8776140 PMID: 35055744

Taylor, T. R., Kamarch, T. W., & Shiffman, S. (2004). Validation of the detroit area study discrimination scale in a community sample of older African American adults: The pittsburgh healthy heart project. *International Journal of Behavioral Medicine, 11,* 88–94. https://doi.org/10.1207/s15327558ijbm1102_4

Tegally, H., Moir, M., Everatt, J., Giovanetti, M., Scheepers, C., Wilkinson, E., et al. (2022). Emergence of SARS-CoV-2 Omicron lineages BA.4 and BA.5 in South Africa. *Nature Medicine, 28,* 1785–1790. https://doi.org/10.1038/s41591-022-01911-2

Thompson, H. S., Manning, M., Mitchell, J., Kim, S., Harper, F. W. K., Cresswell, S., et al. (2021). Factors associated with racial/ethnic group-based medical mistrust and perspectives on COVID-19 vaccine trial participation and vaccine uptake in the US. *JAMA Network Open,* 4. https://doi.org/10.1001/jamanetworkopen.2021.11629.e2111629-e2111629.

Tram, K. H., Seed, S., Bradley, C., Fox, B., Eshun-Wilson, L., Mody, A., et al. (2021). Deliberation, Dissent, and Distrust: Understanding distinct drivers of COVID-19 vaccine hesitancy in the United States. *Clinical Infectious Diseases,* 74(8), 1429–1441. https://doi.org/10.1093/cid/ciaa623

US Census Bureau. (2020). *Current population survey sampling weights.* March 2020.

U.S. Equal Employment Opportunity Commission. What is employment discrimination?. https://www.eeoc.gov/youth/what-employment-discrimination. (Accessed 24 May 2022).

U.S. Food & Drug Administration. (2020). *FDA takes key action in fight against COVID-19 By issuing emergency use authorization for first COVID-19 vaccine.* FDA. https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-issues-emergency-use-authorization-first-covid-19-vaccine Boosters. (Accessed 14 September 2022).

U.S. Food & Drug Administration. (2021a). *Coronavirus (COVID-19) update: FDA expands eligibility for COVID-19 vaccine boosters.* https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-expands-eligibility-covid-19-vaccine-boosters. (Accessed 14 September 2022) Accessed.

U.S. Food & Drug Administration. (2021b). *FDA approves first COVID-19 vaccine.* https://www.fda.gov/news-events/press-announcements/fda-approves-first-covid-19-vaccine. (Accessed 14 September 2022) Accessed.

U.S. Food & Drug Administration. Coronavirus (COVID-19) update: FDA Authorizes Moderna, pfizer-BioNTech bivalent COVID-19 vaccines for use as a booster dose. http://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-moderna-pfizer-biontech-bivalent-covid-19-vaccines-use. (Accessed 14 September 2022).

Van Scoy, L. J., Snyder, B., Miller, E. L., Toyobo, O., Grewel, A., Hu, G., et al. (2021). Public anxiety and distrust due to perceived politicization and media sensationalism during early COVID-19 media messaging. *Journal of Communication in Healthcare,* 14, 193–205.

Williamson, L. D., & Bigman, C. A. (2018). A systematic review of medical mistrust measures. *Patient Education and Counseling,* 101, 1786–1794. https://doi.org/10.1016/j.pec.2018.05.007

Williams, D. R., Yan, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health: Socio-economic status, stress and discrimination. *Journal of Health Psychology,* 2, 335–351. https://doi.org/10.1177/13591053970020305

Yeager, D. S., Kronick, J. A., Chang, L., Javitz, H. S., Levendusky, M. S., Simpser, A., et al. (2011). Comparing the accuracy of RDD telephone surveys and internet surveys conducted with probability and non-probability samples. *Public Opinion Quarterly,* 75, 709–747.

Zhang, X., Guo, Y., Zhou, Q., Tan, Z., & Cao, J. (2021). The mediating roles of medical mistrust, knowledge, confidence and complacency of vaccines in the pathways from conspiracy beliefs to vaccine hesitancy. *Basel: Vaccines,* 9, 1342, 11th ed.