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How trust in cancer information has changed in the era of COVID-19: Patterns by race and ethnicity

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Abstract

COVID-19 emerged during an era of heightened attention to systemic racism and the spread of misinformation. This context may have impacted public trust in health information about chronic diseases like cancer. Here, we examine data from the 2018 and 2020 Health Information National Trends Survey (N=7,369) to describe how trust in cancer information from government health agencies, doctors, family and friends, charitable organizations, and religious organizations changed after COVID-19 became a pandemic, and whether that change varied by race/ethnicity. Statistical methods included chi-square tests and multiple logistic regression modeling. Overall, the proportion of respondents who reported a high degree of trust in cancer information from doctors increased (73.65% vs. 77.34%, p=0.04). Trends for trust in information from government health agencies and family and friends varied significantly by race/ethnicity, with substantial declines observed among non-Hispanic Blacks (NHB) only. The odds of reporting a high degree of trust in cancer information from government health agencies and friends and family decreased by 53% (OR=0.47, 95% CI=0.24 - 0.93) and 73% (OR=0.27, 95% CI=0.09-0.82), respectively, among NHB, but were stable for other groups. Future studies should monitor whether recent declines in trust among NHB persist and unfavorably impact participation in preventive care.

Keywords

Trust; Cancer; Health Communication; Health Survey; Disparities

Background

Trust-related barriers to the utilization of preventive care services like routine cancer screening and HPV vaccination are well documented among vulnerable populations (Adams, Richmond, Corbie-Smith, & Powell, 2017; Alexandraki & Mooradian, 2010; Harrington, Chen, O'Reilly, & Fang, 2021; Musa, Schulz, Harris, Silverman, & Thomas, 2009). Although cancer screening and vaccination rates in the US have rebounded

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considerably after dramatic declines in the early months of the COVID-19 pandemic (e.g. due to stay-at-home orders and service suspensions), racial/ethnic disparities have largely persisted and, in some cases, widened (DeGroff et al., 2021; Labaki et al., 2021; Marcondes, Cheng, Warner, Kamran, & Haas, 2021; Murthy et al., 2021; Santoli, 2020; Whaley et al., 2020). Understanding how the context of COVID-19 has impacted public trust in disease prevention messaging is highly relevant to cancer control in populations at risk of experiencing a disproportionate cancer burden.

In the United States, COVID-19 emerged and evolved during an era of heightened attention to social threats like systemic racism, politically motivated disinformation campaigns, and the proliferation of misinformation generally across social media and news outlets (Auxier, 2020; Bailey, Feldman, & Bassett, 2020; Egede & Walker, 2020; Horowitz, Parker, Brown, & Cox, 2020; World Health Organization, 2020a). It is widely recognized that these factors intersected with and undermined public trust in national efforts to control the pandemic (Galea & Abdalla, 2020; Jaiswal, LoSchiavo, & Perlman, 2020; Loomba, de Figueiredo, Piatek, de Graaf, & Larson, 2021; Mitchell, Jurkowitz, Oliphant, & Shearer, 2020; Vraga & Bode, 2021). For example, conflicting and inconsistent health messaging from government leadership, and the politicization of public health measures like masking and social distancing, contributed to widespread uncertainty around the origin, severity, and prevention of COVID-19 in the US (Balog-Way & McComas, 2020; Chung & Jones-Jang, 2021; Van Kessel & Quinn, 2020). The disproportionate burden of COVID-19 among minoritized racial/ethnic groups amplified the visibility of longstanding structural inequities in healthcare delivery and access (Bhala, Curry, Martineau, Agyemang, & Bhopal, 2020; Metzl, Maybank, & De Maio, 2020; Webb Hooper, Nápoles, & Pérez-Stable, 2020; Williams & Cooper, 2020), and concern around COVID-19 vaccine hesitancy renewed attention to the legacy of medical mistrust, rooted in centuries of unequal care, unethical experimentation and misconduct in government-sponsored research, among Black and African Americans (Marcelin et al., 2021; Warren, Forrow, Hodge, & Truog, 2020; Whetten et al., 2006).

Examining trust in different sources of health information is essential for understanding how the public participates in disease prevention strategies. During novel health crises like COVID-19, government and other national health agencies play an important role in delivering health information, as Americans frequently rely on those agencies to guide health-related decision making when their personal understanding of a disease is limited (Peterson, Chou, Kelley, & Hesse, 2020). The impact of public health messaging from national sources is largely dependent on the public's perception of their work as trustworthy, and mistrust can lead to adverse consequences for disease control (Peterson et al., 2020). In the context of COVID-19, mistrust in government has been linked to lower vaccine acceptance and less participation in behaviors like masking and social distancing (Fridman, Lucas, Henke, & Zigler, 2020; Lindholt, Jørgensen, Bor, & Petersen, 2021). As a digital "infodemic" has grown parallel to the pandemic, trust in information (and misinformation) from informal sources has also impacted COVID-19 mitigation; for example, individuals with a high degree of trust in health information on social media (e.g. Facebook and Twitter) tend to have lower COVID-19 knowledge and are less likely to adhere to social distancing (Fridman et al., 2020).

Trust-related factors are also critical for supporting the control of preventable chronic diseases like cancer. Several factors that have challenged COVID-19 control in the US overlap with cancer control: persistent structural inequities in healthcare that drive disparities in disease screening and mortality (Zavala et al., 2021), exposure to changing and sometimes conflicting guidance on cancer prevention and screening recommendations over time and from different national agencies and organizations (Allen et al., 2013; Nagler, Fowler, Marino, Mentzer, & Gollust, 2019), and the impact of historically rooted governmental and medical mistrust on the acceptability of prevention strategies like HPV vaccination among Black Americans (Fu, Zimet, Latkin, & Joseph, 2017; Harrington et al., 2021; Nan et al., 2019; Yang, Matthews, & Hillemeier, 2011). Little is known, however, about the extent to which trust in cancer information has changed since COVID-19 became a global pandemic. Considering the historical context of the pandemic, trajectories of trust in cancer information may have shifted in the population overall, and to varying degrees across racial/ethnic groups. In this study, we analyzed cross-sectional data collected in 2018 and 2020 from nationally representative samples of US adults to explore: (a) whether public trust in information about cancer from a variety of sources differed before and after COVID became a global pandemic, and (b) whether trajectories of trust in those sources varied by race/ethnicity.

Methods

Data sources and sampling methodology

Data for this analysis are from the publicly available Health Information National Trends Survey (HINTS) (Nelson et al., 2004). Sponsored by the US Department of Health and Human Services, HINTS is a nationally representative cross-sectional survey of non-institutionalized adults that focuses primarily on cancer-related knowledge, attitudes and information seeking. The most recent survey iteration (HINTS 5) was administered in four annual cycles from 2017 to 2020; for this study, we merged data from cycles 2 and 4 of HINTS 5 (H5C2 and H5C4), as both cycles contained the dependent variables of interest (Westat & National Cancer Institute, 2018, 2020). Data collection occurred from January 2018 to May 2018 for H5C2, and February 2020 to June 2020 for H5C4. Both cycles were self-administered mailed questionnaires available in English and Spanish. The sampling strategy involved a two-stage design. The first stage selected a stratified random sample of residential addresses, with two strata comprising addresses in areas with either high or low concentrations of minority populations as defined using census tract-level characteristics from the American Community Survey (ACS). The high minority stratum was oversampled to increase the precision of estimates for minority subpopulations. The second stage selected a single adult per household using the Next Birthday Method (Westat & National Cancer Institute, 2018, 2020). The overall response rates were 32.9% for H5C2 and 36.7% for H5C4 (Westat & National Cancer Institute, 2018, 2020).

Measures

Dependent variables—This analysis involves five dependent variables representing trust in cancer information from the following sources: 1) government health agencies, 2) doctors, 3) family and friends, 4) charitable organizations, and 5) religious organizations and leaders.

Participants responded to a set of items phrased as follows: "In general, how much would you trust information about cancer from [*source*]?" Response options were "A lot," "Some," "A little," or "Not at all." We dichotomized responses into two groups representing 1) high trust (participants who responded "A lot") or 2) low/no trust (participants who selected any of the other three response options). The items and response options were identically worded on both survey cycles. As a reference, the distributions of survey responses across the four-level response scale (prior to dichotomization) are included in Supplementary Table 1.

Independent variables—The two primary independent variables of interest were 1) race/ethnicity and 2) time period in relation to the COVID-19 pandemic. The race/ethnicity variable included five mutually exclusive categories: non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian and non-Hispanic Other. The time period variable was a binary indicator of whether a participant's survey was received by HINTS 1) on or before March 11, 2020 (the date that COVID-19 was declared a pandemic by the World Health Organization [WHO])(World Health Organization, 2020b), or 2) after March 11, 2020. We labeled the two time periods "Before Pandemic" and "During Pandemic," respectively. The data from H5C4, which were collected both before and after the WHO pandemic declaration in 2020, included a variable with this information. Approximately one-third of responses from H5C4 (35.3% weighted percentage) were classified as "Before Pandemic" and approximately two-thirds (64.7% weighted percentage) were classified as "During Pandemic." All data collected in 2018 for H5C2 were classified as "Before Pandemic." Sensitivity analyses addressing potential classification-related biases are described in the statistical analysis section below.

Additional sociodemographic characteristics included sex (male or female); age group (four categories representing 18-34 years, 35-39 years, 40-44 years, or 45 years and older); educational attainment (four categories representing less than high school, high school graduate, some college, or college graduate or more); marital status (married/living as married or not married); census region (Northeast, Midwest, South or West) and household income (five categories representing less than $20,000, $20,000 to <$35,000, $35,000 to <$50,000, $50,000 to <$75,000 and $75,000 or more). Marital status was dichotomized from a categorical response scale that included six mutually exclusive options. Response scales for all other independent variables were derived by HINTS and included in the publicly available datasets.

Statistical Analyses

Primary analyses—First, we calculated the proportion of respondents who reported a high degree of trust in cancer information from each source during the two time periods (i.e., before and during the pandemic). We report proportions overall and by race/ethnicity. Wald chi-square tests were used to compare proportions across the two time periods.

We then examined relationships between the dependent and independent variables outlined above using binary logistic regression models. For each of the five dependent variables, the model building process involved three steps. First, we ran a series of unadjusted models regressing trust in cancer information from a given source (high versus low/no trust) onto each independent variable separately. In the second step, we ran a multivariable logistic regression model that included the main effects of race/ethnicity and time period (the two independent variables of primary interest), plus any additional variables that showed statistically significant overall effects in the unadjusted analyses. The third step involved a multivariable model that, in addition to the main effects modeled in step two, specified an interaction between race/ethnicity and time period. If the interaction term was statistically significant, the third model (main effects + interaction) was selected as the final model; otherwise, the second model (main effects only) was selected as the final model. We present odds ratios (OR) with 95% confidence intervals (CI) and p-values for the final adjusted models, with statistical significance set at $p<0.05$. For final models involving an interaction between race/ethnicity and time period, we additionally present a selection of post-hoc ORs reflecting the odds of reporting high versus low/no trust during the pandemic relative to before the pandemic, stratified by race/ethnicity. To adjust for multiple comparisons, the p-values and CIs for stratum-specific ORs in the interaction models were Bonferroni adjusted.

Analyses were performed with SAS software, version 9.4 (SAS Institute, Cary, North Carolina), using procedures that account for complex survey design (namely, proc surveyfreq and proc surveylogistic). All analyses were weighted to be nationally representative. We used full sample weights to calculate population estimates, and jackknife replicate weights to compute variance estimates. Only complete cases (i.e., no missing data on included variables) were analyzed.

Sensitivity analyses—Although the WHO did not declare COVID-19 a pandemic until March 11, 2020, news and media outlets had been reporting on COVID-19 outbreaks abroad and in the US for two months prior (Centers for Disease Control and Prevention, 2020). Thus, H5C4 respondents who returned their surveys prior to the WHO declaration had likely been exposed to messaging around COVID-19, even if the virus had not yet officially been labeled a pandemic. To justify creating a binary time period variable that collapsed all data from H5C2 and some data from H5C4 into a single response level, we compared the "before pandemic" data from each cycle, looking for differences in the response distributions of key variables. Between the H5C2 data and pre-pandemic data from H5C4, we found no statistically significant differences in the distributions of high versus low/no trust in cancer information from any of the five sources. Compared to H5C2 respondents, pre-pandemic H5C4 respondents had a greater proportion of college graduates (28.76% vs. 32.90%), non-Hispanic White respondents (64.77% vs. 70.15%) and married/living as married respondents (59.07% vs. 52.52%). As a sensitivity analysis, we ran models excluding the pre-Pandemic data from H5C4 in 2020 altogether and looked for changes in statistical inferences about time period effects when comparing the H5C2 data (before pandemic) with the H5C4 data received after March 11, 2020 (during pandemic).

Results

Primary analyses

The pooled data from H5C2 and H5C4 included 7,369 respondents. Demographic characteristics of the sample are presented in Table 1. Approximately two thirds of the pooled sample (67.38%) returned their survey before COVID-19 was declared a pandemic. Most participants were non-Hispanic (NH) White (64.05%), 45 years of age or older (59.37%), and had received at least some college education (69.08%).

Trust in information about cancer from government health agencies—Overall, a similar proportion of respondents from the pooled sample reported a high degree of trust in cancer health information from government health agencies before and during the pandemic (26.98% vs. 28.83%, respectively, p=0.41, Table 2). Before the pandemic, NH Black respondents had the greatest proportion of respondents who reported a high degree of trust (37.60%) and NH Other respondents had the lowest proportion (15.70%). For both of those racial/ethnic groups, the proportion reporting a high degree of trust changed significantly during the pandemic, dropping by more than 15 percentage points for NH Black respondents (p<0.01) and increasing by more than 25 points for the NH Other respondents (p=0.04). During the pandemic, NH Black respondents had the lowest proportion reporting a high degree of trust (22.46%), and NH Other respondents had the greatest (41.53%). The final logistic regression model adjusted for sex, age group, marital status and education, and included a statistically significant interaction between time period and race/ethnicity (p=0.02, Table 3). For the NHB respondents, the odds of reporting a high degree of trust were 53% lower during the pandemic (OR=0.47, 95% CI=0.24-0.93, Table 4) than they were before. Within other racial/ethnic groups, the odds of reporting a high degree of trust were not statistically significantly different during the pandemic relative to before the pandemic.

Trust in information about cancer from doctors—Overall, there was a statistically significant increase in the proportion of HINTS respondents who reported a high degree of trust in cancer information from doctors (73.65% before the pandemic vs. 77.34% during the pandemic, p=0.04, Table 2); differences within racial/ethnic strata were not statistically significant. The final logistic regression model for trust in cancer information from doctors included main effects only, as the interaction between race/ethnicity and time period was not statistically significant. In the final main effects model, race/ethnicity and age were significantly associated with odds of reporting a high degree of trust in cancer information from doctors. Specifically, Hispanic respondents had 29% lower odds of reporting a high degree of trust relative to NH White respondents (OR=0.71, 95% CI=0.53-0.95, p=0.02, Table 3). Relative to respondents 18-34 years of age, the odds of reporting a high degree of trust were 45% lower for those 35-39 years of age (OR=0.55, 95% CI=0.35-0.88, p=0.01), 38% lower for those 40-44 years of age (OR=0.62, 95% CI=0.40-0.97, p=0.04) and 39% lower for respondents of 45 years and older (OR=0.61, 95% CI=0.45-0.82, p<0.01). In unadjusted analyses, higher educational attainment and household income tended to be positively associated with trust in cancer information from doctors, but these effects were not statistically significant in the adjusted model.

Trust in information about cancer from family and friends—Overall, there was not a statistically significant difference in the proportion of respondents before and during the pandemic who reported a high degree of trust in cancer information from family and friends (10.09% vs. 9.75%, p=0.81, Table 2); however, among the NH Black respondents, the proportion significantly decreased by 13.26 percentage points (19.37% before the pandemic versus 6.11% during the pandemic, p<0.01, Table 2). Whereas trust in cancer information from family and friends was highest among the NH Black respondents before the pandemic, it was lowest among NH Black respondents during the pandemic. The final logistic regression model for trust in cancer information from family and friends controlled for educational attainment and included a statistically significant interaction between time period and race/ethnicity (p=0.04, Table 3). The interaction was driven by the change among NHB; During the pandemic, NH Black respondents were 73% less likely than they were before the pandemic to report a high degree of trust in cancer information from family and friends (OR=0.27, 95% CI=0.09-0.82, p=0.01, Table 4), while the difference was not statistically significant within other racial/ethnic groups. Educational attainment tended to be negatively associated with trust in cancer information from friends and family. In the final adjusted analysis, respondents who had graduated college had 53% lower odds of reporting a high degree of trust than respondents with less than a high school education, although statistical significance of this association was marginal (OR=0.47, 95% CI=0.22-1.04, p=0.06, Table 3).

Trust in information about cancer from charitable organizations—Trust in cancer information from charitable organizations did not vary significantly overall, or within racial/ethnic strata, before and during the pandemic. The final adjusted logistic regression model included the main effects of time period and race/ethnicity only; no other potential covariates were statistically significant in the unadjusted analyses, and the interaction between time period and race/ethnicity was not statistically significant in the interaction model. In the final model, only race/ethnicity was statistically significant (p<0.01). Relative to NH White respondents, NH Black respondents had 2.43 times the odds of reporting a high degree of trust in cancer information from charitable organizations (95% CI=1.56-3.77, p<0.01, Table 3), and Hispanics had 1.80 times the odds (95% CI=1.19-2.73, p<0.01, Table 3).

Trust in information about cancer from religious organizations and leaders—Although there was no overall difference in the proportion of respondents who reported a high degree of trust in cancer information from religious organizations and leaders before and during the pandemic, the proportion declined significantly by 9.04 percentage points among NH Black respondents (17.53% vs. 8.50%, p=0.05, Table 2). Educational attainment and household income were significantly associated with trust in religious organizations and leaders in unadjusted analyses and were entered into the adjusted models. Adjusting for education and income, the interaction between time period and race/ethnicity was not statistically significant, and the final adjusted model included main effects only. The odds of reporting a high degree of trust in religious organizations and leaders among NH Black respondents were three-fold that among NH White respondents (OR=3.02, 95% CI=1.80-5.09, p<0.01, Table 3). College graduates had 78% lower odds of reporting a high degree of trust relative to individuals with less than a high school education (OR=0.22, 95% CI=0.07-0.70, p=0.01, Table 3), and individuals with a household income of at least $75,000 had 57% lower odds of reporting a high degree of trust compared to individuals with a household income of less than $20,000 (OR=0.43, 95% CI=0.24-0.80, p<0.01, Table 3).

Sensitivity analyses

In the sensitivity analyses that excluded pre-Pandemic data from H5C4, the results were similar overall. The difference in the proportion of respondents reporting a high degree of trust in cancer information from government health agencies before and during the pandemic was statistically significant for NHB respondents only (38.12% vs. 22.46%, p<0.01). All other statistical inferences around the overall and racial/ethnic group-specific differences in the proportion of respondents reporting a high degree of trust before and during the pandemic (i.e., in doctors, family and friends, charitable organizations and religious organizations and leaders) were consistent with the primary analyses. Results of the logistic regression models were also generally consistent with those from the primary analyses. The interaction between time period and race/ethnicity was statistically significant in the final model for trust in cancer information from government health agencies, and the post-hoc stratum-specific OR for NHB respondents during versus before the pandemic (OR=0.47, 95% CI=0.22-1.00, p=0.05) was similar to that from the primary analysis. The interaction between time period and race/ethnicity was not statistically significant in the adjusted model of trust in family and friends; however, post-hoc ORs stratified by race were of similar magnitude as those from the primary analyses (albeit not statistically significant). In the final model of trust in doctors, the overall effect of race/ethnicity did not reach statistical significance as it did in the primary analyses, but point estimates for each category were in the same direction and of similar magnitude. In the final models for trust in charitable organizations and religious organizations and leaders, all statistical inferences regarding the effects of time period and race/ethnicity were the same.

Discussion

In the United States, COVID-19 emerged amid elevated sociopolitical tensions, heightened visibility of racial inequity, and widespread concern about the dissemination of misinformation on media platforms (Berkowitz, Cené, & Chatterjee, 2020; Egede & Walker, 2020; Zarocostas, 2020). Responses to the ongoing pandemic are highly politicized, with governmental agencies and leaders providing guidance that is at times inconsistent and contradictory to scientific consensus (Bruine de Bruin, Saw, & Goldman, 2020; Gollust, Nagler, & Fowler, 2020; Kim & Kreps, 2020; Ruisch et al.). In light of this climate, we sought to evaluate whether public trust in cancer messaging from governmental, clinical, social and community sources has changed among adults in the US since COVID-19 became a global pandemic, and how that change has varied by race/ethnicity. The results suggest that, overall, trust in cancer information from doctors has increased since March 2020. For NH Black respondents, however, there was a consistent downward trend for trust in cancer information from a variety of sources, namely government health agencies, family and friends, and religious organizations and leaders.

Overall, racial/ethnic trends around trust in cancer information before the pandemic were largely consistent with findings from earlier HINTS cycles; for example, prior pooled analyses of HINTS data have similarly demonstrated that NH Black and Hispanic respondents tend to have higher levels of trust in health information from government health agencies, family and friends, and religious organizations and leaders compared to their NH White counterparts, and lower levels of trust in doctors (Fareed, Swoboda, Jonnalagadda, Walker, & Huerta, 2021; Jackson, Peterson, Blake, Coa, & Chou, 2019). The stability of racial/ethnic trends on trust-related items in HINTS, for more than a decade before the emergence of COVID-19, makes the contrast of response patterns during the early months of the pandemic especially striking. On several items in this study, racial/ethnic patterns changed not only in magnitude, but in direction as well; regarding information about cancer from government health agencies and family and friends, NH Black respondents went from having the greatest proportion respondents with a high degree of trust before the pandemic to the lowest proportion within the first several months of the pandemic.

Public trust in government health agencies enhances the uptake of disease control efforts at the population level. With respect to the COVID-19 pandemic, studies have shown that trust in government is positively associated with favorable behaviors and attitudes, like social distancing, masking, and vaccine acceptability (Han et al., 2021; Trent, Seale, Chughtai, Salmon, & MacIntyre, 2021). Among the NHB population, specifically, qualitative research has highlighted how government distrust, and the history of medical experimentation and research misconduct in the US, have contributed to skepticism around vaccine safety and suspicion toward the motives behind vaccine campaigns (Kricorian & Turner, 2021; Momplaisir et al., 2021; Razai, Osama, McKechnie, & Majeed, 2021). These associations are not unique to the context of COVID-19. For example, lower trust in government has also been associated with HPV vaccine hesitancy among NH Black populations (Nan et al., 2019). The findings from this study suggest that trust in cancer information from government health agencies has decreased among NH Black people, a population that experiences a disproportionate burden of cancers that are preventable, screenable, and optimally treated at early stages (Singh & Jemal, 2017; Zavala et al., 2021). Whether the recent decline in government trust among NH Black respondents will translate to reduced uptake of cancer control measures like HPV vaccination or cancer screening in the long-term remains to be seen. It will be important to monitor whether the patterns observed in this study persist in future HINTS cycle (Gallup polling indicates that by 2021, early changes in Americans' confidence in a number of institutions, including the medical system, had attenuated to more typical pre-pandemic levels (Brenan, 2021)), and whether disparities in HPV vaccination uptake and screening appear or widen in the coming years as a result.

Despite the downward trend among NH Black respondents for trust in cancer information from social, religious and government sources, trust in information from doctors remained stable among NH Blacks and increased modestly in the population overall. This finding is consistent with Gallup poll data showing an increase in Americans' overall confidence in the medical system in 2020 (Brenan, 2021). The stability of trust in doctors is promising for cancer control, considering prior research which has demonstrated that patients are more likely to participate in health behaviors like cancer screening if they receive a recommendation to do so from a physician (Peterson et al., 2016). However, this finding also highlights the importance of addressing 1) inequitable healthcare access, which limits opportunities to receive clinical counseling on preventive services, and 2) evidence that Black and Hispanic patients are less likely to report receiving a provider recommendation for services like screening, related clinical follow-up, and HPV vaccination, even after controlling for markers of socioeconomic status and healthcare access (Ahmed, Pelletier, Winter, & Albatineh, 2013; Coleman Wallace, Baltrus, Wallace, Blumenthal, & Rust, 2013; Ford, Tarraf, Williams, Roman, & Leach, 2021; Kong et al., 2021). Expanding provider training on implicit racial/ethnic and socioeconomic biases and patient-centered communication with underserved populations is warranted, both to engender trust and to leverage the strength of provider recommendations on preventive service utilization. Individual providers and healthcare centers may not be equipped to solve broad social inequities that disenfranchise vulnerable populations from the healthcare system at large. However, As Jaiswal and Halkitis recently concluded in their review, social inequalities drive mistrust (2019). A recent Edelman poll found that most respondents identified health companies' engagement in issues like poverty and income equality, and racial injustice, as at least moderately important for earning and sustaining their trust (Edelman, 2022). For healthcare systems and public health agencies to increase their trustworthiness, formally adopting health equity frameworks that drive the strategic design and impact evaluation of community outreach and engagement efforts may go a long way (Bailey et al., 2020).

Historically, delivering health programming in community- and faith-based settings, and leveraging the social networks and support systems therein, have been important strategies for public health interventions designed to reach minoritized racial/ethnic groups, and populations with limited access to the formal healthcare system (Brewer & Williams, 2019; Debnam, Holt, Clark, Roth, & Southward, 2012; Newlin, Dyess, Allard, Chase, & Melkus, 2012). This history makes the loss of trust in family, friends, and religious organizations among NH Black respondents particularly worrisome. To bolster trust in cancer information from these sources moving forward, strengthening partnerships between community-based organizations (including churches and other settings that are part of a community's social fabric) and outreach and engagement teams from local healthcare institutions may be an important strategy. Involving nurses in the delivery of cancer prevention messaging and services in community-based settings may be particularly beneficial. While the HINTS survey did not ask respondents to rate their trust in cancer information from nurses, specifically, national polls show that for twenty years, US adults have consistently rated the honesty and ethical standards of nurses higher than those of other professionals, including medical doctors (Gallup, 2022).

This study had several strengths. First, HINTS comprises a nationally representative sample, which enhances the generalizability of our findings to the US adult population. Second, we conducted several sensitivity analyses that produced generally consistent results. Where statistical inferences in the sensitivity analyses differed from those of the primary analyses, estimated effect sizes tended to be similar. This suggests that significance tests in the sensitivity analyses were underpowered due to smaller sample sizes.

This study also had several important limitations. First, we were unable to examine specific mechanisms underlying the temporal changes to trust in cancer information at the population level. In addition to the cross-sectional design of HINTS, the data instruments were designed and deployed before important historic events in 2020 unfolded, thereby precluding the measurement of unanticipated mediating factors (e.g., confidence in the government response to COVID-19) that may have impacted trajectories of trust in cancer information. The confusion and controversy surrounding the US pandemic response, which informed our hypothesis, was one part of the larger social, political, or historical tapestry of 2020. Thus, it is unclear whether the time period effects observed in this study are directly attributable to poor pandemic-related communication. Politically charged messaging around COVID-19 and heightened media attention to institutional racism and racial inequities may have intensified historically rooted distrust among NH Black people. Qualitative research may be particularly beneficial for further understanding the nature and complexity of these relationships.

A related caveat is that we have limited ability to identify when the decreasing trends of trust among the NH Black population began, and whether those trends were linear over time. It is possible that mistrust in cancer information from government health agencies began before news of COVID-19 emerged, and the decline in trust may be related to other preceding factors such as the 2020 presidential election campaigns, some of which spanned over two years. It is reasonable to question the suitability of using a binary time-period variable where a single "before pandemic" response level was applied to all data from 2018 *and* pre-pandemic data from 2020. To justify this coding, we compared response distributions on the dependent variables between the 2018 data and pre-pandemic data from 2020. There were no statistically significant differences in the overall proportions of participants reporting a high degree of trust in each of the five sources. The differences were also not statistically significant when stratified by race, but confidence was limited by the small sample sizes on which the significance tests were based.

Due to sample size limitations, we were unable to evaluate trends in small but important population subgroups, like American Indians and Alaskan Natives (AIAN), who were also disproportionately impacted by the COVID-19 pandemic (Williamson et al., 2021). HINTS survey respondents may identify as belonging to any of 19 distinct races and five Hispanic ethnicity classifications. From this data, HINTS derives 5- and 7-level race/ethnicity variables. Because AIAN and Native Hawaiians and other Pacific Islanders (NHPI) had small sample sizes (e.g., unweighted n=10 and n=15, respectively, in H5C4), there was limited statistical power to detect significant effects within those groups. Thus, we chose to use the 5-level variable, which collapses AIAN, NHPI and non-Hispanic respondents who selected multiple races into a single "NH Other" response category. It is challenging to interpret the meaningfulness of observed effects among the "NH Other" group, considering the racial/ethnic heterogeneity it encompasses.

In fact, even defined racial/ethnic categorizations are not monoliths, and population-level trends patterned by race/ethnicity do not apply universally at the individual-level. There may be important sources of variability within racial/ethnic groups that were not specified in our models and thus masked. Our primary hypothesis was that trust in cancer information changed differentially among racial/ethnic groups since the pandemic, and we tested this hypothesis by specifying a two-way *time period*race/ethnicity* interaction term. In future research, additional higher order interactions could, in theory, capture temporal trends of trust in cancer information at various intersections of race/ethnicity and other social forces (e.g., gender and class). Robust empirical methods are needed for incorporating intersectional approaches into population health research.

Conclusion

The unprecedented sociopolitical context surrounding the COVID-19 pandemic undermined adherence to policies and recommendations designed to prevent viral spread. Concurrently, longstanding racial/ethnic disparities in outcomes of chronic diseases such as cancer were exacerbated due to several factors like limited access to care and health system capacity. It is yet to be determined whether there will be longer-term impacts of mistrust in cancer information from governmental and social sources on cancer-related health behaviors, especially among racial/ethnic groups that already bear a disproportionate burden of treatable chronic disease. This study is significant because it provides early insight into the actions we may need to take to rebuild trust in health information as a means to advance health equity in spite of the societal shifts that have accompanied the COVID-19 pandemic. Downward trending trust in cancer information from authorities like government health agencies suggests it will be important to monitor for changing patterns in the utilization of cancer prevention services that could, in turn, exacerbate racial/ethnic disparities in cancer morbidity and mortality. Sustained trust in cancer information from doctors emphasizes the importance of: continued efforts to combat implicit biases and strengthen patient-centered approaches within the clinical setting, so that physician recommendations for preventive care are communicated effectively and equitably across patient populations; organizational adoption of health equity frameworks to guide community outreach and advocacy around access to preventive care for marginalized populations; and bolstering partnerships between healthcare systems and community-based organizations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Characteristics of respondents from HINTS 5, Cycle 2 (2018) and Cycle 4 (2020)

	N[**]	Weighted percentage
Pooled sample total	7369	100.00
Time-period[*] (n=7369)		
Before pandemic	4941	67.38
During pandemic	2428	32.62
Sex (n=7213)		
Male	2955	48.71
Female	4258	51.29
Race/Ethnicity (n=6641)		
NH White	4116	64.05
NH Black	925	10.99
Hispanic	1057	16.49
NH Asian	299	5.18
NH Other	244	3.29
Age Group (n=7155)		
18-34	890	24.89
35-39	412	6.94
40-44	455	8.80
45+	5398	59.37
Household Income (n=6535)		
Less than $20,000	1203	16.36
$20,000 to < $35,000	879	11.65
$35,000 to < $50,000	864	13.09
$50,000 to < $75,000	1159	18.04
$75,000 or More	2430	40.86
Education (n=7175)		
Less than high school	548	8.51
High school graduate	1336	22.42
Some College	2120	39.56
College graduate or more	3171	29.52
Marital Status (n=7170)		
Married/Living as married	3725	53.66
Not married	3445	46.34
Census Region (n=7369)		
Northeast	1107	17.67
Midwest	1283	20.91
South	3248	37.79
West	1731	23.63

[*] "Before pandemic" includes HINTS 5 Cycle 4 survey data received on or before March 11, 2020 and all HINTS 5 Cycle 2 survey data. "During pandemic" includes HINTS 5 Cycle 4 survey data received after March 11, 2020.

[**] Raw frequencies (not weighted)

Table 2.

Trust in cancer information before and during the COVID-19 pandemic, by information source and race/ethnicity, among HINTS 5 Cycle 2 and Cycle 4 respondents

A. Trust in information about cancer from government health agencies

	Percentage of respondents reporting a high degree of trust*			
	Before pandemic****	**During pandemic******	**Difference**	***p-value* *****
Overall	26.98	28.83	1.85	*0.41*
Non-Hispanic White	24.15	26.33	2.18	*0.44*
Non-Hispanic Black	37.60	22.46	−15.14	***<0.01***
Hispanic	35.53	38.67	3.14	*0.64*
Non-Hispanic Asian	37.55	39.49	1.93	*0.83*
Non-Hispanic Other	15.70	41.53	25.84	**0.04**

B. Trust in information about cancer from doctors

	Percentage of respondents reporting a high degree of trust*			
	Before pandemic****	**During pandemic******	**Difference**	***p-value* *****
Overall	73.65	77.34	3.69	**0.04**
Non-Hispanic White	76.24	80.18	3.93	*0.10*
Non-Hispanic Black	72.80	75.91	3.10	*0.56*
Hispanic	68.70	73.22	4.52	*0.33*
Non-Hispanic Asian	72.81	80.61	7.81	*0.22*
Non-Hispanic Other	62.89	82.80	19.91	*0.06*

C. Trust in information about cancer from family and friends

	Percentage of respondents reporting a high degree of trust*			
	Before pandemic****	**During pandemic******	**Difference**	***p-value* *****
Overall	10.09	9.75	−0.34	*0.81*
Non-Hispanic White	9.12	10.65	1.53	*0.45*
Non-Hispanic Black	19.37	6.11	−13.26	***<0.01***
Hispanic	9.69	8.81	−0.88	*0.82*
Non-Hispanic Asian	5.83	9.22	3.39	*0.52*
Non-Hispanic Other	7.48	18.11	10.64	*0.40*

D. Trust in information about cancer from charitable organizations

	Percentage of respondents reporting a high degree of trust*			
	Before pandemic****	**During pandemic******	**Difference**	***p-value* *****
Overall	9.48	9.26	−0.22	*0.87*
Non-Hispanic White	7.92	7.53	−0.39	*0.78*
Non-Hispanic Black	17.70	15.78	−1.92	*0.75*
Hispanic	13.89	12.01	−1.88	*0.64*
Non-Hispanic Asian	7.57	6.00	−1.57	*0.65*
Non-Hispanic Other	6.74	22.40	15.66	*0.25*

A. Trust in information about cancer from government health agencies				
	Percentage of respondents reporting a high degree of trust[*]			
	Before pandemic[**]	**During pandemic**[**]	**Difference**	***p-value*** [***]

E. Trust in information about cancer from religious organizations and leaders				
	Percentage of respondents reporting a high degree of trust[*]			
	Before pandemic[**]	**During pandemic**[**]	**Difference**	***p-value*** [***]
Overall	6.00	6.06	0.06	*0.96*
Non-Hispanic White	3.45	4.81	1.35	*0.42*
Non-Hispanic Black	17.53	8.50	−9.04	***0.05***
Hispanic	8.34	8.59	0.26	*0.93*
Non-Hispanic Asian	3.62	1.70	−1.93	*0.37*
Non-Hispanic Other	2.27	16.23	13.96	*0.28*

[*] High trust indicated by the response "A lot" to the item, "In general, how much would you trust information about cancer from government health agencies?" Alternative response options included "Not at all," "A little" or "Some"; these responses were grouped into a single category representing low/no trust.

[**] "Before pandemic" includes HINTS 5 Cycle 4 survey data received on or before March 11, 2020 and all HINTS 5 Cycle 2 survey data. "During pandemic" includes HINTS 5 Cycle 4 survey data received after March 11, 2020.

[***] Wald chi-square tests; results statistically significant at p<0.05 in bold

Table 3.

Odds ratios from logistic regression models of trust in cancer information from various sources among HINTS 5 Cycle 2 and Cycle 4 respondents

	Government health agencies		**Doctors**		**Friends and family**		**Charitable organizations**		**Religious organizations**	
	Final model: main effects + interaction		**Final model: main effects only**		**Final model: main effects + interaction**		**Final model: main effects only**		**Final model: main effects only**	
	OR (95% CI)	***p-value***	**OR (95% CI)**	***p-value***	**OR (95% CI)**	***p-value***	**OR (95% CI)**	***p-value***	**OR (95% CI)**	***p-value***
Time Period**										
Before Pandemic	***	***	*(ref)*		***	***	*(ref)*		*(ref)*	
During Pandemic			1.21 (0.97 - 1.52)	*0.09*			0.95 (0.70 - 1.29)	*0.74*	0.96 (0.58 - 1.60)	*0.89*
Race-Ethnicity				***0.04***				***<0.01***		***<0.01***
NH White	***	***	*(ref)*		***	***	*(ref)*		*(ref)*	
NH Black			0.82 (0.60 - 1.11)	*0.20*			**2.43 (1.56 - 3.77)**	***<0.01***	**3.02 (1.80 - 5.09)**	***<0.01***
Hispanic			**0.71 (0.53 - 0.95)**	***0.02***			**1.80 (1.19 - 2.73)**	***0.01***	1.36 (0.73 - 2.54)	*0.33*
NH Asian			0.84 (0.56 - 1.28)	*0.42*			0.90 (0.52 - 1.54)	*0.69*	0.83 (0.32 - 2.20)	*0.71*
NH Other			0.53 (0.27 - 1.04)	*0.06*			1.39 (0.54 - 3.57)	*0.49*	0.59 (0.17 - 2.00)	*0.39*
Sex			NA		NA		NA		NA	
Male	*(ref)*									
Female	1.23 (0.99 - 1.51)	0.06								
Age Group		**0.01**		***0.01***	NA		NA		NA	
18-34	*(ref)*		*(ref)*							
35-39	0.75 (0.51 - 1.09)	0.13	**0.55 (0.35 - 0.88)**	***0.01***						
40-44	0.81 (0.54 - 1.22)	0.31	**0.62 (0.40 - 0.97)**	***0.04***						
45+	**0.60 (0.45 - 0.81)**	**<0.01**	**0.61 (0.45 - 0.82)**	***<0.01***						
Education		**<0.01**		*0.35*		**0.04**				***0.01***
Less than high school	*(ref)*		*(ref)*		*(ref)*				*(ref)*	
High school graduate	0.76 (0.50 - 1.16)	0.21	1.15 (0.72 - 1.85)	*0.55*	0.78 (0.35 - 1.78)	0.56			0.46 (0.15 - 1.41)	*0.17*
Some College	1.03 (0.69 - 1.53)	0.90	1.22 (0.78 – 1.91)	*0.39*	0.62 (0.29 – 1.35)	0.23			0.35 (0.11 – 1.09)	*0.07*
College graduate	1.47 (1.00 – 2.17)	0.05	1.42 (0.88 – 2.29)	*0.15*	0.47 (0.22 – 1.04)	0.06			**0.22 (0.07 – 0.70)**	***0.01***
Household Income	NA			*0.36*	NA		NA			***<0.01***

	Government health agencies		**Doctors**		**Friends and family**		**Charitable organizations**		**Religious organizations**	
	Final model: main effects + interaction		**Final model: main effects only**		**Final model: main effects + interaction**		**Final model: main effects only**		**Final model: main effects only**	
	OR (95% CI)	***p-value***	**OR (95% CI)**	***p-value***	**OR (95% CI)**	***p-value***	**OR (95% CI)**	***p-value***	**OR (95% CI)**	***p-value***
Less than $20,000			*(ref)*						*(ref)*	
$20,000 to < $35,000			0.92 (0.64 – 1.30)	*0.62*					1.07 (0.59 – 1.94)	*0.82*
$35,000 to < $50,000			0.82 (0.56 – 1.20)	*0.30*					0.99 (0.49 – 2.03)	*0.98*
$50,000 to < $75,000			0.95 (0.66 – 1.36)	*0.77*					1.08 (0.47 – 2.51)	*0.85*
$75,000 or More			1.10 (0.80 – 1.52)	*0.55*					**0.43 (0.24 – 0.80)**	***0.01***
Marital Status			NA		NA		NA		NA	
Married/Living as	*(ref)*									
Not married	1.17 (0.97 – 1.41)	0.10								
Census Region	NA		NA		NA		NA		NA	
Northeast										
Midwest										
South										
West										
Time Period *x* Race/Ethnicity[**]	*[***]*	***0.02***		*NA*	*[***]*	***0.04***		*NA*		*NA*

NH=non-Hispanic; OR=Odds Ratio; CI=Confidence Interval; NA = Not Applicable (i.e., unadjusted association was not statistically significant, and covariate was excluded from subsequent modeling steps).

Estimates statistically significant at p<0.05 in bold

[**] "Before pandemic" includes HINTS 5 Cycle 4 survey data received on or before March 11, 2020 and all HINTS 5 Cycle 2 (2018) survey data. "During pandemic" includes HINTS 5 Cycle 4 survey data received after March 11, 2020.

[***] For final model estimates involving terms in interaction, see selected pairwise odds ratios in Table 4.

Table 4.

Odds of reporting a high degree of trust in cancer information from selected sources during the pandemic relative to before the pandemic, stratified by race/ethnicity, among HINTS 5 cycle 2 and cycle 4 respondents

A. Trust in government health agencies		
	OR (95% CI)	***p-value***
Racial/Ethnic Group		
NH White	1.07 (0.72 - 1.58)	*1.00*
NH Black	0.47 (0.24 - 0.93)	***0.02***
Hispanic	1.05 (0.48 - 2.30)	*1.00*
NH Asian	1.06 (0.41 - 2.7)	*1.00*
NH Other	3.82 (0.70 - 20.90)	*0.20*
B. Trust in family and friends		
	OR (95% CI)	***p-value***
Racial/Ethnic Group		
NH White	1.16 (0.64 - 2.12)	*1.00*
NH Black	0.27 (0.09 - 0.82)	***0.01***
Hispanic	0.87 (0.24 - 3.13)	*1.00*
NH Asian	1.64 (0.15 - 17.56)	*1.00*
NH Other	3.48 (0.12 - 101.64)	*1.00*

NH=non-Hispanic; OR=Odds Ratio; CI=Confidence Interval

CIs and p-values Bonferroni adjusted for multiple comparisons