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"You don't trust a government vaccine": Narratives of Institutional Trust and Influenza Vaccination among African American and White Adults

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Abstract

Vaccine confidence depends on trust in vaccines as products and trust in the system that produces them. In the US, this system consists of a complex network connecting pharmaceutical companies, government agencies, and the healthcare system. We explore narratives from White and African American adults describing their trust in these institutions, with a focus on influenza vaccine. Our data were collected between 2012 and 2014 as part of a mixed-methods investigation of racial disparities in influenza immunization. We interviewed 119 adults, primarily in Maryland and Washington, DC, in three stages utilizing semi-structured interviews (12), focus groups (9, n=91), and in-depth interviews (16). Analysis was guided by grounded theory. Trust in institutions emerged as a significant theme, with marked differences by race. In 2018, we contextualized these findings within the growing scholarship on trust and vaccines. Most participants distrusted pharmaceutical companies, which were viewed to be motivated by profit. Trust in government varied. Whites described implicit trust of federal institutions but questioned their competency. African Americans were less trusting of the government and were more likely to doubt its motives. Trust in institutions may be fragile, and once damaged, may take considerable time and effort to repair.

Keywords

Influenza Vaccine; Trust; Race; Pharmaceutical Companies; Government; Institutions; African Americans; USA

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1. Introduction

Medical research continues to affirm the safety, efficacy, and value of vaccination, yet vaccine hesitancy and refusal continue to undermine immunization campaigns worldwide (MacDonald, 2015). The World Health Organization (WHO) uses the concept of "vaccine hesitancy" to characterize this issue, defining it as the "delay in acceptance or refusal of vaccines despite availability of vaccination services" (WHO, 2014). In this conceptualization, vaccine hesitancy is influenced by three factors: complacency, convenience, and confidence, where confidence represents, "trust in the 1) effectiveness and safety of vaccines, 2) the system that delivers them, including the reliability and competence of health services and professionals, and 3) the motivations of policy-makers who decide on the needed vaccines" (MacDonald, 2015, p.4162). Scholars worldwide have embraced this framework, but conceptual ambiguities remain, particularly related to the role of trust (Peretti-Watel et al. 2015).

In the US, seasonal influenza vaccine is recommended to all adults and is widely available at low or no cost (Grohskopf et al. 2018). However, adult influenza immunization rates continue to be suboptimal. In the 2017–18 flu season, only 37% of adults were vaccinated, far below the 70% goal set by Healthy People 2020 (CDC, 2018a; U.S. DHHS, 2015). African Americans are significantly less likely to be immunized than Whites, with a longstanding disparity in vaccination rates (Lu et al. 2014). We believe that low confidence in influenza vaccines may contribute to low vaccination rates overall and the ongoing racial disparity, as evidence suggests African Americans may be less trusting of institutions that are involved in vaccine production and promotion (Freimuth et al., 2017; Quinn et al. 2018; Musa et al. 2009).

1.1 Trust and Vaccines

The WHO's Strategic Advisory Group of Experts (SAGE) on immunization has led efforts to conceptualize and assess the role of public trust in immunization. SAGE is responsible for the working definitions of vaccine hesitancy and efforts to develop scales of both vaccine hesitancy and confidence (Larson et al. 2014; Larson et al. 2015; MacDonald, 2015). While researchers agree that trust is fundamental to public acceptance of vaccines, there is less agreement on how trust should be defined or measured, which aspects of trust should be considered, and which relationships should be studied (Larson et al. 2018). This is not unique to the study of vaccines, but rather reflects the ambiguities of trust as a concept.

Embedded in the SAGE definition of confidence is the delineation between "the reliability and competence of health services and professionals" (MacDonald, 2015 p.4162). This distinction reflects the dual aspects of trust described in the Trust Confidence and Cooperation (TCC) Model, which distinguishes between "social trust" based on similarity and "shared values" and confidence based on past experience (Siegrist, Earle & Gutscher, 2003). These two dimensions have also been described as "trust in motives" and "trust in competence" (Twyman, Harve, & Harris, 2008). In both conceptualizations, increased social trust (or trust in motives) and confidence (or trust in competence) are believed to increase cooperation (or greater trust overall) (Twyman et al., 2008; Siegrist et al.,2003). Both

dimensions have been hypothesized to correlate with increased vaccine uptake and intentions (Larson et al. 2018).

1.2 Background Literature

The decline in public trust towards vaccination is a global issue (Larson, 2016). Many possible explanations for this decline have been hypothesized, including vaccine safety scares, the rise of anti-vaccine groups, the use of social media, the idea that vaccines have been "victims of their own success", and rising distrust of "expert" culture in general (Larson et al. 2014; Dube et al. 2015; Yaqub et al. 2014). The relationship between distrust and decreased vaccine uptake has made vaccine skeptics and non-vaccinators a common research focus. One major theme is that in the absence of trust towards experts and other authority figures, individuals may feel the need to "re-interpret" vaccine information themselves (Yaqub et al. 2014). Others have highlighted how broader social trends may influence trust, as modern patients are encouraged to be "advocates" for their children's health and to take an active role in decision-making (Hobson-West, 2007). Sometimes, a vaccine scare, negative publicity, or other public incident can contribute to longterm declines in trust (King & Leask, 2017). It is important to note that factors may vary by community, as "local vaccine cultures" based on shared experiences and social norms are a powerful influence on vaccine acceptance and refusal (Streefland et al. 1999).

A 2018 literature review documented 35 articles covering a broad range of topics related to trust and vaccines (Larson et al.2018). The subset of studies focused on trust in the healthcare system and trust in government were largely quantitative, with the majority concluding that greater trust was associated with increased intention to vaccinate (Larson et al.2018). Among the qualitative studies focused on institutional trust, common themes were identified around distrust of pharmaceutical companies and the importance of history in shaping trust relationships (Larson et al. 2018). The vaccine hesitancy framework emphasizes that confidence in vaccines is context specific, so while this growing body of literature reflects some commonalities, each population, vaccine, and geographic area constitutes a unique case.

1.3 Influenza Vaccine Production and Regulation in the US

Confidence in an influenza vaccine also depends on trust in the many actors and agencies responsible for the production, regulation, and administration of the vaccine. Briefly, we highlight the key actors and their roles in this network. Our focus is on the role of institutions in the US, with a focus on influenza vaccines for adults. There are three key players: the pharmaceutical companies that develop and produce the vaccines, the Food and Drug Administration (FDA) that regulates flu vaccine production, and the Centers for Disease Control and Prevention (CDC) that sets vaccine recommendations and promotes the vaccine to the public.

Influenza vaccines are unique in that they are reformulated annually, and recommendations are updated every year. The WHO predicts the dominant influenza strains each season, and the Food and Drug Administration (FDA) decides which strains to include in FDA-licensed vaccines (Weir & Guber, 2016). All vaccine manufacturers undergo extensive testing and

need to be relicensed from the FDA annually (Weir & Gruber, 2016). Only a few pharmaceutical companies (Sanofi Pasteur, GlaxoSmithKline, and Seqirus) produce influenza vaccines for the US, partially due to the costs involved in vaccine development and partially due to the challenges associated with influenza vaccine (FDA, 2018; Houser & Subbaro, 2015). Once vaccines are ready for the public, the Advisory Committee on Immunization Practices (ACIP), a 15 member panel of experts appointed by the CDC, releases updated recommendations for vaccination (CDC, 2015). The CDC also conducts public health campaigns to promote influenza vaccination, in some instances subsidizing the cost of flu vaccines for certain populations including low-income children and uninsured adults (CDC, 2018b). Once on the market, the CDC and the FDA continue to monitor vaccine safety through the Vaccine Adverse Event Reporting System (VAERS) (CDC, 2015).

We recognized a gap in the literature surrounding the particular context of our work: narratives of institutional trust as it relates to adult seasonal influenza vaccination in the US. This data had been collected as part of a broader study of factors influencing racial disparities in adult influenza immunization, where we identified trust as one of many influences on vaccine decision-making (Quinn et al. 2016). Those findings informed the development of survey items, which when administered in a national survey confirmed significant differences in trust between African Americans and Whites (Freimuth et al. 2017). In this manuscript, we explore institutional trust related to influenza vaccine using narratives from African American and White adults.

2. Methods

2.1 Study Design & Procedure

This manuscript is based on data collected between 2012–2014 as part of a mixed-methods investigation of racial disparities in influenza vaccine uptake. For our qualitative data collection and analysis, we employed grounded theory to guide our research. Grounded theory depends on successive stages of data collection interspersed with analysis, allowing for emergent themes in the data to be fully explored (Glaser & Strauss, 1968). Our process involved data collection in three phases: exploratory interviews, focus groups, and in-depth interviews. Recruitment strategies varied by phase but relied on print and online advertising in campus and local newspapers, online advertisement through list serves and social media platforms, distribution of flyers, and targeted recruitment through community partners in the Maryland Community Research Advisory Board (MD-CRAB).

First, we engaged in exploratory, semi-structured, in-person interviews (n=12) with African American and White adults to identify key themes related to adult influenza immunization. Initial interviews utilized open-ended questions and probes to elicit general attitudes related to influenza vaccine. We utilized a convenience sample at this stage, recruiting primarily through the MD-CRAB and community partners.

Next, we organized nine focus groups (n=91) in the Washington, DC metropolitan area and along Maryland's rural eastern shore. These groups were arranged by race (6 African American, 3 White), past vaccine behavior (3 never vaccinated, 3 always vaccinated, 3

mixed), and geography (3 rural, 6 urban/suburban). We engaged in purposive sampling, pre-screening potential participants over the phone to ensure diversity not only in race and vaccine behavior, but also in key demographics including age, sex, and educational background. Each 90 minutes focus group was moderated by a professional researcher of the same race as the participants. Moderators followed a "funnel approach", asking open-ended questions and gently guiding discussions while still allowing conversation to flow freely (Morgan, 1996).

After an intensive period of qualitative coding and analysis, we conducted additional in-depth interviews (n=16), to follow up with specific themes that remained unexplored. At this point in the analysis, trust in institutions had emerged as a significant theme and the interview protocol included several questions on trust and distrust. In these interviews, we engaged in purposive sampling across demographic groups and intentionally oversampled individuals who had not been vaccinated for influenza.

Eligible participants included adults (over 18 years of age) native to the US who self-identified as either White or African American. We focused on these two groups to better understand the entrenched racial disparity in immunization rates. We obtained approval from the Institutional Review Board of the University of Maryland. Prior to participation, all individuals were guided through the informed consent process by researchers specifically trained to conduct informed consent with racially diverse populations. Names and identifying information were omitted from transcripts. Participants received gift card incentives ranging from $30-$50 for participation.

2.2 Data Analysis

All interviews and focus groups were audio recorded and professionally transcribed. A team of qualitative researchers developed a codebook combining deductive and inductive codes. Utilizing Atlas.TI Qualitative Software, each transcript was first annotated independently; annotations were then discussed between the two annotators until reaching consensus. In this way, the codebook grew to accommodate new and emergent ideas. The initial codebook consisted of deductive codes covering general topic areas like "communication" and "risk" but grew over the course of analysis to include over 100 unique and increasingly specific codes. In this period, significant themes were identified and written up into semi-formal memos. Memo-writing is a crucial step in grounded theory. Memos serve as a place to document analytical breakthroughs, identify patterns, expand upon emerging themes and relationships, and can serve as the foundation of theory (Charmaz, 2006). We used memos to document significant themes and returned to them regularly throughout the analysis process.

Initial analysis was completed in 2014. We published a broad overview of all qualitative findings in 2016 that touched upon our trust-related findings and a quantitative assessment of racial differences in trust based on a national survey in 2017 (Quinn et al. 2016; Quinn et al. 2017). In 2018, reflecting on outstanding research questions, we decided to assess our qualitative data with a specific focus on institutional trust. To do this, we engaged in a focused analysis of key quotes identified under the broad code 'trust', and the specific codes 'guinea pigs', 'they' distrust, conspiracy theories, government competence, trust government, trust healthcare industry, trust pharmaceutical companies, trust vaccine, race

and trust, and age and trust. Excerpts were not re-annotated, but we reconsidered the relationships between the individual codes. We also returned to our original memo written on racial differences in trust, reconsidering our initial conclusions through the lens of current literature and theory, as well as the results from our own quantitative research.

3. Results

Our findings suggest that for most adults, trusting a flu vaccine necessarily involves trust relationships with multiple entities and individuals. Two distinct areas of focus were clear in the narratives: trust in pharmaceutical companies and the healthcare industry, and trust in the government, including federal public health agencies. In total, we talked with 119 adults about their attitudes, which included more African Americans than Whites, more females than males, and more older adults (>50) than younger people (Table 1). To identify quotes, we use the following short hand: race (AA=African American, W=White), vaccine uptake (T=taker, NT=non-taker), and gender (M= male, F= female) (Table 2). In the process of transcribing focus groups and preserving anonymity, it wasn't always possible to attribute all details to every quote.

3.1 Pharmaceutical Companies and the Healthcare Industry

3.1.1 Profits—Respondents expressed serious concerns regarding the "*for profit*" nature of the healthcare industry. Nearly all respondents who shared opinions on the subject expressed concern that the healthcare industry valued profit over the needs of the public. Pharmaceutical companies were viewed with deep distrust. One woman explains, *"I don't trust them. I don't think they have the consumers' best interest at heart. I think they are all about the dollar sign, and so therefore I don't trust them. They lost their way somewhere, whereas it's not for the better of the people, it's to line our coffers" (WNTF).*

Influenza vaccines served as a particular trigger for these anxieties. Some viewed the need to re-vaccinate annually with suspicion. Some people saw pharmaceutical companies making a greater profit by offering a yearly vaccine, a sentiment described as *"the money is in the medicine, not in the cure"(AANTF).* This notion that a pharmaceutical 'cure'for disease would reduce vaccine profits was repeated a few times by different individuals. One man likened the pharmaceutical industry to 'drug dealers', *"These people, it's a business. They don't make money curing you. They make money selling you drugs. They're drug dealers" (AAM).*

For others, in addition to increasing revenue, yearly vaccination was viewed as a cover for low vaccine efficacy, as this woman explains, "*I'm not sure the vaccine works. I think it might be a big hype by the pharmaceutical companies to get more money. I'm very skeptical of the pharmaceutical companies, and that they're just making everybody think they need this, but what are your chances of actually getting the flu every year, I don't know. So, I have my doubts" (WNTF).* Even adults who got the vaccine expressed doubts about the need for annual vaccination. We heard, *"It's all based on the money thing. And if people think it comes out every year in such large amounts, and to such a large population, they see that, okay, let's do this every year and so it changes, and so forth. But it also comes down to the money" (WTF).*

The price of influenza vaccines was a concern for many respondents. There were adults who questioned that if the vaccine was truly was so important, why wasn't it free? Under the Patient Protection and Affordable Care Act of 2010, insurance companies were required to cover the cost of influenza immunizations, but it was unclear whether participants were aware of this policy change. For some, this reflected their distrust of the industry's motives, as described by this woman, *"…why aren't you just giving it away? Because the pharmaceutical company is out there making money from it. So, I don't mind them making money, but not off of death. Because, to me, that just reeks of capitalism that I just really don't like. You're not really concerned about me as much as you are about your financial bottom line" (AANTF).* For those who had faith in the vaccine's effectiveness, the idea of pharmaceutical companies profiting off vaccines was morally repugnant. One woman explains:

> I think that, and this is just from a social standpoint, it should not be that big a profit margin. It should be, because it's something that can be preventable and especially for children and the elderly and for those communities that are lesser served, it should be, I wouldn't say free, but really for children I think it should be free… I think for the elderly I don't think it should be a charge for it. But I don't think it should be a profit making venture, because they make so much profit on other pharmaceuticals (AATF).

Interestingly, none of our respondents indicated the cost alone was the reason that they had forgone a vaccine.

3.1.2 Corrupting the System—In some instances, individual concerns about profits were bigger than the influenza vaccine; instead, they saw the entire industry as the problem. Although our questions and prompts were specific to influenza vaccine, sometimes responses were much broader. One man focused on the business practices of the pharmaceutical companies: *"The drug companies seem to peddle a lot of things. I mean there are a lot of conditions that I never heard of when I was a little guy that seem to suddenly be on the TV screen or on a billboard or something, and so that doesn't seem, you know..." (WNTM).* There was the insinuation that the drug companies create drugs with side effects so severe that they require even more new drugs, *"You don't find out about the negative side effects of it until later…So you do have to feel that you're sort of the test dummy for a lot of these drugs (AANTF)."* One man pointed out how things have changed over time, implicating both direct-to-consumer advertising and the medicalization of social concerns to generate sales.

We heard that this money could be a corrupting influence through the entire vaccine production chain, negatively influencing all parties involved. Pharmaceutical profits took away from the healthcare system, *"I don't even know where it is broken, but to me the ones that I see making the billions and billions of dollars are the pharmaceutical companies. It's not the doctors anymore. It's not the hospitals, for sure. But the pharmaceutical companies are making the money" (WNTF).* Others saw profits trickling into practice, motivating providers to recommend vaccines to make money *"…Doctors make a lot of money because lots of times they work with the pharmaceutical people and there's a lot behind closed doors*

that we never know about with this stuff…But they're getting kickbacks and the pharmaceutical companies are just making money hand over fist" (WTF). A woman summarized the way money connected the entire system, *"And it goes back to the bigger picture, which is the pediatrician, or the pharmacist, or the doctor, what have you, only want the money… They're going to feed you and feed you as much as you can…You know all this money, money, money, money. Pay me. Pay me. Pay me. Pay me" (AANTF).*

3.2 Government

3.2.1 Race and Trust—Participants expressed a broader range of attitudes related to the government's role in flu vaccination, with opinions ranging from complete trust to complete suspicion. These differences tended to fall along racial lines. African Americans often introduced the topic of government trust. In a focus group, a woman exclaimed, *"You don't trust a government vaccine!"* When the moderator probed, she explained, "*I don't trust the government for nothing that they're mixing up" (AANTF).* Participants attributed the origin of this distrust to their race. One man described it as "*a natural mistrust*" *(AATM).* A woman characterized it as "*cultural conditioning,"* suggesting:

> I just think over time, you know, we've just heard foolish things like, 'Those doctors are trying to kill you. They're trying to put something in that stuff that's going to erase us and get us out of here,' you know, all that just being drilled in, you know, generation after generation after generation (AANTF).

For some African Americans, this distrust is bigger than vaccines, as one former Marine explained*, "… I have major trust issues with my government across the board… A lot of people are trust motivated. If you don't have my trust then I'm not going to pay you much mind no matter what you say" (AAM).*

In contrast, White respondents rarely introduced topics related to trust in the government on their own. Many of the comments from Whites came in response to specific questions about trust. More Whites describing trust as implicit or inherent, such as this woman, *"I'm a trusting person. That's why it's so unimportant. Inherently it's there" (WTF),* or another woman, *"I just inherently trust that the product and the people are honest and truthful in what I'm getting" (WTF).*

3.2.2 The Role of History—The most commonly repeated justification for racial differences in trust was history. African Americans were clear that race, more than any other factor, was the primary issue: "*Well, African American folks, they don't really trust as much as White—you know, as White Americans trust, because you know due to this history of slavery and the whole nine yards, they just a little bit – they doubt a little bit*" *(AANTM).* Discussions of medical racism centered on the infamous Tuskegee Syphilis Study, which ran from 1932–1972 and involved a cohort of African American men who were intentionally denied treatment for Syphilis, even after a safe and effective cure was made available (Jones, 1993). While participants talked about the Tuskegee study, we found that this discussion was typically tied to a larger context of injustices both past and present, *"…different things that have been done to us in the past. A certain portion of that is still holding true for a lot of us.*

We're not trusting" (AANTF). The general sentiment was that medical abuses had occurred, but more importantly, they may still be occurring. One woman described her concerns:

> But that is why – it is because of the history of the medical industry and its distrust on how they treated African Americans. And like I said, at that time they didn't even view us as human beings so they felt that they could do whatever they wanted to do. But I just, I haven't seen where they have tried to build the trust. It's like, "Okay that happened 100 years ago. Don't worry about it." But I think there are probably more instances. We just don't know about them and they hide them. So, I don't want to end up with this, this will come out, "10 years ago, guess what, when you had this vaccine back in 2004 guess what was in it?" because that can happen" (AANTF).

In these discussions, African Americans were more likely to describe the history in general terms without detailing personal encounters.

The absence of these kinds of stories from White narratives was notable. However, rather than drawing attention to positive experiences, a few White respondents simply remarked that nothing bad had happened to them. These equivocal experiences were still used to bolster trust: *"I have to trust somebody, and I mean I haven't had really any bad experiences with doctors or hospitals or medications, whatever, so I know that they exist, and I know that sometimes people get screwed, but I don't really have a better option" (WNTF).* It is important to note, that this woman recognized that some people get "*screwed*" but implies it isn't people like her. Similarly, Whites were unlikely to suspect ulterior motives for vaccination, *"For flu vaccine, absolutely not. It probably wouldn't cross my mind. I never thought, "I'm not going to get a flu vaccine because I think they're experimenting on me" (WNTM).* Unlike the African Americans who spoke of history more broadly, many Whites referred more narrowly to their personal experiences.

3.2.3 Generational Differences—While the general attitude from African American focus groups was one of distrust, some younger participants hinted that this may be changing. For their generation, some recent improvements led them to feel more positively towards the government, *"However, most of us, I'm glad to say, or it seems, have loosened that mistrust. I trust people… I trust you, but I got to verify it. So we've come a long way. So has the government. So have those that run the government" (AATM).* When African Americans described trust, it was clear they were making conscious choices to trust,

> I trust them, and I'm going to tell you why… Because if they were, if I felt like I couldn't trust them that I means I can't trust everybody's that's working with them. There are too many people that work in the government that have our best interest. So, please don't think that the government is trying to hurt us if they say, 'Go get your flu shot.' Because I don't believe they are, period (AAM).

African Americans were clear that the older generation was less trusting of the government and of influenza vaccines than the younger generation, *"I think the older generation, you hate to sa,y set in their ways, but it's a pattern that they associated with fear of what the government may do the unknown. I think that is something that still has not changed even to this day" (AAM).* But for Whites, the older adults attributed their own trust on their

upbringing and were more likely to see younger adults as those with lower trust. An older man explained,

> I mean it's generational. I was raised during the Second World War and we did everything the government said to do. I mean that was it, 'Sure.' And now people are much more individualistic, they don't want to be bossed around, and they're also more paranoid…The way I was raised the thought of not doing what I was told to do, I mean in a community type of thing, it's good to get a vaccination, everybody needs to have one, fine I'll do it (WTM).

A much younger woman mirrors this description, explaining how her she views her parents' generation, *"They would do what the doctor says. It's part of what he was talking about, the acculturation of 'you do what the government tells you to do'. You do what the doctor says" (WTF).*

3.2.4 Specific Agencies—Another racial difference was centered on the perceptions and language used to describe the federal agencies involved in flu vaccination. African Americans were more likely to use the term "government" broadly. Whites were more likely to name specific agencies, *"So yeah, I think that the CDC and NIH, all those government health organizations, aren't going to put you at risk of excess harm if it's not necessary. So I have a lot of trust in what they recommend" (WTF).* Whites also described differing levels of trust by agency, *"I guess I would tend to view different agencies really differently, and I don't know if that's something that is common. I trust the Centers for Disease Control. I trust the National Institute of Health. I don't trust the CIA*" (*WTF*).

Of these named public health agencies, the FDA was the least trusted, in part due to perceived ties to the pharmaceutical industry. A woman explained, *"So, there is probably a little bit of trust issues with the FDA too that they don't always do the right thing for the consumer. Again it's their connection with those pharmaceutical companies and all that." (WNT).* Another participant articulated his concern that even if the FDA was distinct from the industry, lobbyists had too much influence:

> Well, I mean I know that we have the FDA and such to regulate things. Now where their allegiances lie is a whole different question. There are lobbyists, and if you look at some of the people that-- I don't know specifically right now about who is on the FDA and who is serving in what capacity, but if you look into it very far, you'll see a lot that were like first pretty high up at Pfizer and then was on the FDA and then went back to some other drug company. So, there is an uncomfortably tight linkage between those two (WNTM).

Interestingly, the few African Americans who did voice agency-specific trust concerns were focused on the CDC, and not the FDA. In a focus group, a younger African American woman explained, *"It was the CDC and I think it was the public health service that was behind the Tuskegee experiment, and all of the things you hear now are coming from the CDC about the flu this and the flu that…" (AANTF).*

3.2.5 Competence and Motives—Many African Americans voiced deep-seated distrust of the government's motives, pointing to racism in history and discrimination in the

present to justify these fears. The idea that the government would engage in illicit activity was common theme among African Americans, who did not hesitate to describe *"cover ups",* or stories of adulterated vaccines, and suspicions of humans used as "*guinea pigs".* The general attitude was that, "*I think the government does have power to hide what they don't want us to see" (AANTF).* In contrast, it didn't occur to many of our White respondents to question government motives. Instead, high levels of trust were the norm, "*So yes, I trust that the FDA is doing its job and the CDC is doing its job in the public interest" (WTF).*

Whites didn't question motives; instead, participants questioned the competency of the government. Many concluded the government was competent. A man explained, *"I trust the system. I don't worry about that. I don't have the feeling that people are slacking off on creating the best vaccine possible without any contamination in the serum or anything like that. I don't worry about that" (WNTM).* Another woman explained, *"I feel comfortable that the vaccine I have is authentic. I guess that is a better word maybe instead of some sort of counterfeit. I don't know why you would have counterfeit vaccine, but whatever. That I trust the product and trust the people" (WTF).*

4. Discussion

These narratives add depth to ongoing discussions of institutional trust and influenza vaccination, particularly in the context of racial disparities in the United States. We find that when assessing trust in influenza vaccines, trust levels vary significantly by institution. Most respondents, White and African American, young and old, vaccinated and not, were aligned in distrusting pharmaceutical company motives. Trust in government agencies was more nuanced with clear divisions across racial and generational lines. While there are parallels to other studies from around the world, the context specific nature of vaccine hesitancy and confidence makes our findings a necessary contribution to this literature. Our focus is unique in several ways: first, the topic of seasonal influenza vaccine means these trust relationships are reconsidered year after year; second, we rely on adults describing their own vaccine decisions, which may be substantially different than studies assessing parents making vaccine decisions for their children; and third, rather than focusing only on vaccine hesitant individuals, we explored trust in both vaccinated and unvaccinated individuals and explored reasons for both trust and distrust. Perhaps most significantly, our findings are deeply rooted in American culture and history, as the racialized history of American healthcare continues to impact the ways individuals, both African American and White, interact with the entities involved in the vaccine process.

We know that the complex and specialized knowledge required to make a fully informed choice about vaccination requires most individuals to make assessments based on trust in the source of information rather than on specific content (Brownlie & Howson, 2005). In healthcare, Brown observed a "will to trust" where individuals are eager to trust expert opinions, to reduce the anxiety and uncertainty associated with medical procedures (Brown, 2009). In practice, this may mean that most adults trust vaccines to overcome both the complexity of the system that produces vaccines and also to overcome "incomplete knowledge" of vaccine science and risks (Attwell et al. 2017). However, recent scholarship

has emphasized a shift away from vaccine refusal as a "knowledge deficit" problem (that individuals are uninformed or misinformed) and towards a broader understanding of the role of distrust in the sources of information and in the healthcare system more broadly (Yaqub et al. 2014; Hobson-West, 2007; Goldenberg, 2016). Our findings reflect this complexity. We saw that regardless of background knowledge, participants articulated their concerns about influenza vaccines primarily through the lens of trust.

We found pharmaceutical companies inspire little trust, primarily because individuals suspect that the motives governing these institutions are more aligned to generating profit than serving the public good and that pharmaceutical profits corrupt the entire healthcare industry. This is similar to what has been described elsewhere, most notably by Atwell and colleagues who document non-vaccinating parents' using the idea of a "puppet master" to describe the influence of pharmaceutical companies over the entire healthcare system in Australia (Attwell, 2017; Sobo et al. 2016). We observe that this attitude is shaped by the expansion of pharmaceutical interests in American culture more broadly, compounded by modern direct-to-consumer advertising techniques and the explosion in so-called "designer drugs", both of which give the impression that pharmaceutical products are simply seeking to increase profits. As a result, some American consumers see the recommendation for an annual flu vaccine as a marketing ploy. With such high levels of distrust, any communication or efforts from pharmaceutical companies to directly influence vaccine campaigns are not likely to be successful. However, technical breakthroughs (i.e., a universal flu vaccine replacing annual immunization, improved vaccine effectiveness, increasing vaccine supply, and streamlining vaccine distribution) could reduce some of issues that concern participants, and perhaps indirectly influence trust.

The true novelty of our findings is in the clear documentation of divisions of trust along racial lines. There is no simple way to fully explain the clear racial differences, but the concept of white privilege needs to be introduced. While it has been defined in several ways, one relevant definition comes from Kendall (2006) who defines white privilege as "an institutional, rather than personal, set of benefits granted to people whose race resembles that of the people who are in power" (p. 63). In our results, many African Americans grappled with a racist past and continued discrimination in the present, which means that for many, trusting an influenza vaccine requires overcoming distrust. However, for Whites, the lack of similar discrimination and generally positive experiences with the healthcare system and federal institutions creates an environment where historically, trust comes naturally and is not necessarily questioned. Some scholars, notably Reich, have highlighted how vaccine choice in itself is an act of privilege, which is certainly true, but we also believe that the ability to "opt-out" of making a considered choice reflects another aspect of privilege (Reich, 2014). We also recognize that race is not the only source of discrimination, and in other contexts, factors including class, education, or ethnicity could be significant.

As several African American participants pointed out, the fear that injustices may still be occurring is widespread in the community. The high levels of distrust towards the government voiced by African Americans were not surprising, as in our national survey, we found African Americans were less trusting than Whites of all institutions involved in

influenza vaccine production, including pharmaceutical companies, the FDA, and the CDC (Freimuth et al. 2017).

In the US, race significantly impacts the quality of healthcare an individual receives. One does not need to look far to see examples of racial injustice negatively impacting the health of minority communities, from the ongoing water contamination crisis in the low-income, majority-Black, city of Flint Michigan, to the steady rise in maternal mortality for African American mothers across the country, and proliferation of police shootings of unarmed Black men. In the SAGE discussion of vaccine confidence, context, including societal and historical factors, is considered, and clearly, the broader societal context of discrimination, including in health care, impacts trust and affects decision making about the influenza vaccine (MacDonald, 2015).

We saw generational patterns in institutional trust but with major differences by race. In the ways that White participants described high levels of institutional trust, we saw echoes of what Attwell described as "uncritical trust" where social norms allowed for a "suspension" of uncertainty (2017). In the past, a cultural emphasis on "*doing what you're told*" and respecting the hierarchies embedded in the healthcare system may have contributed to the high levels of vaccine uptake but masked any personal misgivings. Today, individuals are encouraged to exercise personal choice, serve as "advocates" for their own health and the health of their families, and actively engage healthcare decisions, which may lead to questioning the authority of experts (Reich, 2014; Attwell et al. 2017). This cultural shift may explain the generational divide we observed among Whites, with higher trust observed among older Whites and more open skepticism from younger Whites.

In contrast to the "uncritical trust" described by so many White participants, African Americans were more likely to describe active engagement in deliberations of trust. Younger African Americans were more willing to trust and described the older generation as "*stuck in their ways*". Allusions to changes in government related to Obama's presidency (2009–2017) may explain some of this optimism. Our findings differ slightly from those of Harris and colleagues, who described elderly (65 and older) African Americans with relatively high trust in institutions, after making a choice to "overcome mistrust of medical institutions and racism" (Harris et al., 2006, p.1682). Perhaps both studies emphasize the same thing, namely, that deciding to trust institutions is an active choice for many African Americans. While some studies have observed the influence of both social class and education level in the rise of vaccine hesitancy, among our sample, the clearest patterns fell along racial and generational divides (Blume, 2006; Reich, 2014).

Interestingly, we observed no clear patterns between expressed trust and influenza vaccine behavior. Many of the comments outlining distrust of pharmaceuticals or wariness of the government's motives came from individuals who indicated that they had been vaccinated. Perhaps this is less surprising that it may seem; turning back to the vaccine hesitancy framework, we recognize that confidence is only part of a more complex set of influences. For instance, the idea that pharmaceutical companies made a profit off vaccines was distasteful to most adults but may not to be enough of a deterrent to opt out of vaccination if perceived risk of disease was high, or if social pressures made it difficult to turn down a

provider recommendation (Quinn et al. 2016). While vaccine uptake is a valuable metric, it is important to note it is not the only measure of hesitancy. Many have observed that vaccine hesitancy falls along a continuum and by monitoring underlying attitudes, such as institutional trust, we can more accurately understand where individuals fall along that spectrum (Streefland et al. 1999; Nichter 1995; Larson et al. 2014; MacDonald, 2015).

The nature of trust is that it must be given freely; it cannot be coerced (Gilson et al. 2003). Indeed, trust relationships need to be actively produced and negotiated (Gilson et al. 2003). Our findings and existing literature suggest that there are distinctions between passive acceptance of vaccines based on “blind” or “implicit” trust and active demand for a vaccine and an informed decision to trust (Nichter, 1995). To increase active demand and encourage greater trust, health care providers may need to engage with patient concerns related to influenza vaccine. In the absence of trust, mandatory vaccination or punitive schemes may backfire (Ward et al. 2018).

Given that the historical and social context in which both African Americans and Whites encounter the flu vaccine differs, and while public health providers and health care professionals cannot remedy legacies of racism and its corollary, privilege, they can recognize that challenge, and take steps to strengthen trust with individuals and populations. Instead of further exploring reasons for minority populations to distrust, it may be time to explore the understudied concept of “trustworthiness” and interrogate whether institutions have done enough to have earned trust (Larson et al. 2018). What actions are necessary to be viewed as trustworthy may differ by agency and by the group making that judgment. Certainly, with widespread perceptions that pharmaceutical lobbies have influence over the FDA, the FDA could enhance its trustworthiness by providing more transparent information on the process of influenza vaccine production, approval and regulation. The CDC could potentially affect trust in the agency by acknowledging and explaining how vaccine effectiveness is assessed and what those measures of effectiveness mean for the public. However, we caution that enhancing the trustworthiness of agencies will require consistent attention to agency actions, including those beyond influenza vaccination, and sensitivity to concerns of minority groups who often have different experiences with government agencies.

4.1 Limitations

Most of our data was collected in Maryland and Washington, DC; adults living here may have different experiences with federal agencies than those living elsewhere. Our data reflects the time at which it was collected, 2012–2014, during the second term of President Obama. This was particularly salient for many of the African Americans we interviewed, particularly those who indicated that “things were changing” in the government. With the new Trump administration, attitudes towards public institutions may have shifted.

5. Conclusions

We assessed racial differences in trust in the influenza vaccine and trust in the system that produces it. Trust in pharmaceutical companies is low, as many participants perceive that companies are motivated by profit and not by serving patients. Trust in the government

varies by race. For many Whites, trust in government's role in influenza vaccination is implicit and unquestioned. For some African Americans, trust in government's role in influenza vaccination is earned only after reconciling injustices of past and addressing present racism. Social, cultural, and historical factors have a major influence on trust in institutions. Trust in these institutions is fragile and once lost may be difficult to regain. Instead of continuing to focus on why minority groups may not be trusting, it may be time for researchers to focus on what institutions can do to increase their trustworthiness.

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Research Highlights

- Trust in flu vaccines may reflect trust in the institutions that produce them
- Pharmaceutical companies are widely distrusted, often due to perceived motives.
- Trust in government differs by race, age and institution.
- White privilege may shape high levels of passive trust among Whites.
- Racialized history continues to shape current attitudes about institutions.

Table 1:

Sample Descriptions

Semi-Structured Interview Sample			
	White (*n*= 5)	**African American (*n*= 7)**	**TOTAL (*n*=12)**
Gender n(%)			
Male	0(0)	5(71)	5(42)
Female	5(100)	2(29)	7(58)
Age Range (Mean)	27–71(46.2)	26–65(41.9)	26–71(43.8)
Education Level n(%)			
High School or Less	1(20)	3(43)	4(33)
Some College	2(40)	2(28)	4(33)
4-Year Degree or Higher	2(40)	2(28)	4(33)

Focus Group Sample By Race			
	White (*n*= 27)	**African American(*n*= 64)**	**TOTAL (*n*=91)**
Gender n(%)			
Male	10(37)	22(34)	32(35)
Female	17(63)	41(64)	58(64)
Other	0(0)	1(2)	1(1)
Age n(%)			
18–29	4(15)	6(9)	10(11)
30–44	6(22)	16(25)	22(24)
45–59	3(11)	27(42)	30(33)
60+	14(52)	15(23)	29(32)
Education n(%)			
High School or Less	0(0)	20(31)	20(22)
Some College	6(22)	25(39)	31(34)
4-Year Degree or Higher	21(28)	19(30)	40(44)

Sample for In-Depth Individual Interviews			
	White (*n*=8)	**African American(*n*=8)**	**TOTAL (*n*=16)**
Gender n(%)			
Female	4(50)	4(50)	8(50)
Male	4 (50)	4(50)	8(50)
Age Range(Mean)	24–67(44.8)	35–72(55)	24–72(49.3)
Education Level n(%)			
High School or less	0(0)	0(0)	0(0)
Some College	1 (12.5)	1(12.5)	2(12.5)
4-Year Degree or Higher	7(87.5)	7(87.5)	14(87.5)

Table 2.

Matrix of participants by race, gender, and vaccine status

	Taker	Non Taker	Unknown	Total
African American Female	12	26	9	47
African American Male	12	17	2	31
White Female	15	10	1	26
White Male	8	6	0	14