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# Civic Learning, Science, and Structural Racism

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If democratic governance in a pluralistic society requires that citizens share a sense of common purpose to solve difficult problems, then we must attend to political, economic, and social forces that corrode this sense. Pervasive racial discrimination in the United States corrodes it by undermining trust in social institutions. Using the case of vaccination against the human papilloma virus as our example, we reflect here on the role that racial discrimination plays in shaping American political life, particularly in shaping the terms of debates about science and medicine.

Rates of vaccination against HPV are very low among Black adolescents. We argue that racism not only limits the willingness of Black mothers to allow their adolescent sons to receive vaccination against HPV, but it also influences their attitudes about medicine, science, and the government. There is broad concern in the Black community that medical professionals and government officials may not operate to promote the interests of Black children. Resistance to the HPV vaccine is not merely a reflection of a lack of knowledge and the need for additional information. It is grounded in a deeply held belief, resulting from and reinforced by historical cases of discrimination in medicine and other domains of life, that medicine and government are willing to inflict harms on racial minorities.<sup>1</sup> If the citizens of the United States hope to encourage deliberation about science and medicine grounded in evidence, it is crucial to better understand and address the reasons that racial and ethnic minorities may be deeply skeptical of medical and scientific institutions.

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## HPV Vaccination in Adolescent Black Males

HPV is the most commonly transmitted infection in the United States. Nearly 80 million Americans are infected with it, and 14 million new cases occur each year.<sup>2</sup> Transmission of the virus occurs via skin-to-skin contact involving the genitals. Low-risk types of HPV can cause genital warts (papillomas) or cellular changes on the cervix.<sup>3</sup> High-risk types can cause abnormal cells to form on the cervix, and those abnormal cell changes can develop over time into cervical cancer if they are not removed. Some infected individuals will clear the virus from their bodies within a few years of the initial infection, but others will not. HPV-associated cancers in men include some anal, penile, oropharyngeal, and oral cavity cancers.<sup>4</sup> Men are at disproportionate risk for oropharyngeal cancer, most likely due to infection with the HPV-16 strain, which is the most common strain of the virus in the oral mucosa. There are significant racial disparities in sexually transmitted infection rates; non-Hispanic Black men have the highest prevalence of overall genital and high-risk oral HPV infections.<sup>5</sup> Even if infected men have no symptoms, they can transmit the virus to their sexual partners.

Fortunately, there are vaccines to protect against HPV, and the best protection occurs when individuals receive the vaccine while free of infection and have time to develop an immune response prior to exposure. The vaccine for HPV consists of virus-like particles that contain components of the real human papilloma virus but lack genetic material (DNA). This makeup has been shown to induce a strong protective immune response. More than 57 million doses have been distributed globally, with no verified major safety concerns. Most side effects related to vaccination are mild and include pain (usually at the injection site), fainting, dizziness, and nausea.

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Vaccination of males provides direct benefits by offering protection against some cancers. In addition, vaccination in males can reduce transmission of high- and low-risk types to female partners and reduce infection, disease, and possible disease in this population as well.<sup>6</sup> Despite research findings that stress the importance of vaccination, uptake remains low among Black male adolescents.

Why are rates of HPV vaccination low in this population? Interviews conducted by one of us (Kiameesha Evans) with mothers of Black male adolescents provide important insights into the reasons for racial disparities in the uptake rates.<sup>7</sup> The interviews focused on the mothers of teens because, in many households, mothers are the primary caretakers and control the health care-related behaviors for their children, such as making and attending medical appointments, filling prescriptions, and paying for health costs. Research with fathers of daughters regarding HPV vaccination suggested that fathers would prefer that mothers handle decisions about their daughter's health care. This sentiment was particularly strong among some Black families.<sup>8</sup>

The Evans study, which included twenty-three interviews with a convenience sample of mothers of adolescent Black males in New Jersey, found that many interviewees expressed concern about allowing their children to receive the HPV vaccine. As with previous studies of vaccination, an array of factors appeared to influence attitudes about vaccines and vaccine uptake. These include awareness of the vaccine, concerns about its safety, and religious beliefs and the concern that HPV vaccination may lead to sexual activity. Along with these factors, skepticism about the HPV vaccine appears to reflect a lack of trust in science, medicine, and the government. As one respondent put it, "I think that the Black community is highly critical and highly distrusting of modern medicine. . . . I think we are very distrusting of doctors. . . . I think we're very fearful that someone is giving us something or testing things out" (Respondent 17).<sup>9</sup> Another woman argued that many people in the community fear that they are victims of a conspiracy. "I think in the African American community," she explained, "there's all of like a conspiracy theory. . . . They don't trust the government period. So, if anything is out by the government or the pharmaceutical companies, you know, there's a distrust there" (Respondent 16). This fear was expressed directly and powerfully by another respondent: "I've heard . . . that in the Black community they usually give some more things that are not good for us,

because they assume we don't know better. I would tend to agree with that. . . . I don't typically take my child to places in Black communities for that purpose. . . . If I know there's a health clinic in my area or an area where there are a lot of Blacks or Hispanics, I don't take my kids" (Respondent 12).

The Black community includes a wide variety of subcommunities, such as African American, West Indian/Caribbean, and those of African descent who have emigrated to the United States. Representatives of these subgroups of the Black community shared different viewpoints about vaccination and potential subsequent behavior in their interviews. Regardless of the mothers' ethnic background, mothers acknowledged, as in the following example, how being Black in America may create pervasive mistrust: "[B]ecause historically African Americans . . . have been exposed to unfortunate medical events and have been experimented on and treated in very inhumane ways, that we probably have a greater sort of doubt and that could also work against us in some ways because we're sometimes less likely to get help and seek the treatment and prevention that we could because we just don't trust the medical professionals" (Respondent 10).

Two participants described different attitudes about vaccination in the West Indian community. One woman, who identified as African American, felt that her African American friends were more critical of her decision to delay vaccination for her son after birth than members of the West Indian community were: "[M]y family and my friends that are African Americans, that are not of Caribbean descent, they thought I was crazy. [laughs] They thought that I should really just kind of get it done. It was my Caribbean American friends that had concerns and had decided it along the way to wait for some of their vaccinations for their children as well" (Respondent 19). The other woman, who identified as West Indian, expressed that those in her West Indian community were more likely to support the recommendations of the health care providers, whereas those in the African American community were more likely to mistrust the health care system: "I almost feel . . . I think West Indian people . . . say, 'The doctor said to do it. Okay.' They question no authority. They don't even try to find out information about it. It's just an immediate, 'Yes.' I would say anybody who has ever made [statements about mistrust of the health care system] to me, are actually African Americans. . . . I don't think it's a bad thing. I think you should question. I think it's cultur-

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ally where West Indians don't question the authority, when they see doctors and lawyers and cops, and they see things like that as authority. They would never question anything" (Respondent 5).

In prior research on medical mistrust in communities of color, study participants have cited the Tuskegee Syphilis Experiment or used phrases like "guinea pigs" and "test dummies."<sup>10</sup> The interviews in the Evans study revealed similar sentiments, even if those exact words were not used. For instance, one mother stated, "I know stories from really back in the day about Black people being vaccinated by what they thought would be one thing and then it was something totally different, so you're basically a guinea pig. So that was a negativity, and unfortunately it really sticks with people to this day" (Respondent 17). Another said, "I think that the Black community is highly critical and highly distrusting of modern medicine. . . . I think we are very distrusting of doctors. . . . I think we're very fearful that someone is giving us something or testing things out" (Respondent 10).

Two mothers explained that their mistrust came from a belief that vaccines are designed for different groups of people. "In our community," one related, "I see it as people are afraid just like they're afraid to go to the doctors because they feel the same thing that we're being put out there as test dummies and guinea pigs to be used on to see how this is gonna react. Then you're wondering are they really putting the actual medicine in or did they single these out and these are for the Black people, these are for the White people. Are they putting something else in there?" (Respondent 12). And the other stated, "I've heard that vaccines, they have a Black vaccine. That's what I've heard. I've heard people say they have Black vaccines, which are vaccines that in the long run make us worse off than if we didn't have the vaccine. So I have some people that say the vaccine actually gives you the actual illness. So people believe that. If they don't get a measles shot, then they'll be better off than getting it, the measles shot, because then they'll get the measles" (Respondent 14).

Yet another respondent explained that she had heard similar things among those she knew in the Black community but that she felt very differently about the concerns raised by some: "Yes, out here people say, 'Vaccines is poison, they trying to poison us.' I say, 'Well, if they're trying to poison us, why everybody getting it?' They don't just say only Black people got to get the vaccine, it's everybody. Black, Spanish, Chinese. . . . I think a lot of that stems back from our reputation in the Black community and not trusting people in research" (Respondent 7).

Mothers' attitudes were shaped by personal, lived experiences as well as perceived experiences shared by those they know. Some mothers chose to vaccinate in spite of their

mistrust. For others, the mistrust weighed heavily in their decision not to vaccinate.

Some scholars have challenged the idea that distrust in the medical profession explains lower rates of vaccination among Black people,<sup>11</sup> but the findings from the Evans study are consistent with other recent studies that attempt to explain low HPV vaccine uptake. For example, Xiaoli Nan and colleagues, in a study of 124 African American custodial parents of children who had not yet been vaccinated for HPV, found that "low trust in health information from government health agencies was associated with less favorable attitudes and intentions toward vaccinating their child against HPV."<sup>12</sup> In this latter study, the role of the government in advocating for vaccine uptake was particularly important. Moreover, this finding does not appear to be unique to HPV. In a study that tried to explain lower uptake of the influenza vaccine among Black people, Amelia Jamison and colleagues argued that the difference was due, in part, to the fact that Black people, in comparison with their White counterparts, "were less trusting of the government and were more likely to doubt its motives."<sup>13</sup>

### Racial Discrimination in Science and Medicine

The lack of trust reflected in attitudes about HPV vaccines is not surprising given the long history of racial discrimination in science and medicine. Much of this distrust stems from infamous examples of discrimination and exploitation in medical research. Most well-known is the Tuskegee syphilis study, started in 1932 and lasting for forty years, in which the U.S. Public Health Service and the Tuskegee Institute studied the natural history of syphilis among six hundred poor African American men in Alabama without seeking informed consent from the study subjects and without ever providing treatment to patients with syphilis, even after penicillin was identified as an effective treatment for the disease in 1947. But while Tuskegee is an important cause of distrust, it is not the only one.<sup>14</sup> In the case of Henrietta Lacks, which was made famous by a 2010 book, a low-income African American woman was used for research and commercial applications without her consent. In 1951, Lacks received treatment for a malignant tumor on her cervix at The Johns Hopkins Hospital. She died from the disease, but researchers at the hospital, who found that her cancer cells had the unusual trait of doubling every twenty to twenty-four hours, made her cells widely available for medical research. These cells have been used by scientists and drug companies for decades even though neither Lacks nor members of her family were aware that her cells had been harvested and had not given permission for them to be used in research.<sup>15</sup>

These episodes continue to resonate today and have a profound impact on the attitudes of Black and brown

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## *It is crucial for medical professionals and researchers to act as antiracists.*

people toward research, the medical profession, and government authorities. Research in communities of color suggests that distrust of the medical system and health professionals (as well as the “stain” of Tuskegee) may remain in some communities.<sup>16</sup> A recent poll by National Public Radio and Harvard University found that one-third of African Americans claimed that they had experienced racist discrimination in a doctor’s office or clinic, and about 20 percent avoid medical care due to fear of discrimination.<sup>17</sup> When it comes to the attitudes of parents about medical care for their children, many studies find that African American parents are more likely than parents of other races to express a lack of trust in doctors and to fear that their children may be subject to inappropriate experimentation.<sup>18</sup>

Beyond problems in medical research, there is extensive evidence of racial and ethnic discrimination in treatment. For decades, scholars have found evidence that there is “de facto racial segregation” in the U.S. health care system. Even after controlling for factors like health status, education level, and insurance status, African American patients are less likely than White patients to receive timely and appropriate ambulatory care, hospitalizations, or surgical interventions.<sup>19</sup>

The relationship between race and access to health care is complex, as some scholars who write about the concept of intersectionality have explained.<sup>20</sup> The idea of intersectionality was first used to explain how Black women’s lived experiences are shaped simultaneously by being Black and by being female, with effects that are qualitatively different from just the combination of being a woman and being an African American. Although intersectionality originated as a way to draw attention to groups and individuals who were hidden, many scholars use the idea of intersectionality to argue that people and institutions must focus on the processes that produce inequality. For example, we—all of us—should examine racism instead of race. This leads to a focus on structures and institutions as fundamentally shaped by, while also producing and reproducing, multiple axes of inequality.

### **The Context of Structural Racism**

**A**s we suggest above, episodes of racial injustice in science and medicine do not happen in a vacuum. These violations and their impact on trust in scientific institutions must be placed in the larger context of structural racism. Structural racism is the idea that political and social

institutions and processes systematically disadvantage some racial and ethnic groups and privilege others. As David Jones explains, structural racism is a helpful framework because it does not focus on the more limited question of whether individual elected officials or other key actors are racist; it leads instead to a focus on the institutions that lock advantage and disadvantage in place.<sup>21</sup>

This structural problem is reflected in racial differences in incarceration rates, poverty, maternal and child mortality, and life expectancy, among other measures. When African Americans and other Black and brown groups interact with government health programs, experts in medical research, or medical professionals, they are not only interacting with institutions and programs that have a poor track record of racial discrimination, but they are doing so in the context of a racially biased political economy. It is crucial for medical professionals and researchers to act as antiracists<sup>22</sup> to counter these forces. As Michele Evans and colleagues explain, physicians sometimes try to build trust by claiming that they “don’t see color.” But by failing to recognize how structural racism has influenced the lives of their patients, they may be “inadvertently feed[ing] the robust structural racism that influences access to care, quality of care, and resultant health disparities.”<sup>23</sup>

Under these circumstances, it would be remarkable if Black and brown patients were *not* skeptical about whether they were being treated appropriately. The more recent rhetoric from now former President Trump and the emboldened white supremacy movement has further exacerbated this situation, reinforced racial divisions within socioeconomic classes, and made it harder to recognize the potential for a multiracial political coalition.<sup>24</sup>

### **Racial Justice and the Capacity for Civic Learning**

**I**f, as citizens, we want to rebuild a capacity for civic learning, we need to acknowledge and address these issues. In the short term, increasing the number of clinicians of color may contribute to the development of better trust between doctors and patients and increase patients’ active participation in their care.<sup>25</sup> More specifically, addressing negative attitudes about vaccination may increase rates of vaccination in the African American population.<sup>26</sup> Studies looking at how to overcome racial disparities in end-of-life care have found that efforts by medical staff to address the concerns of patients directly and provide education can reduce mistrust.<sup>27</sup>

A longer-term solution to this issue requires more. As Gregory Kaebnick explains elsewhere in this special report, we cannot hope to bring about more productive conversations about issues like vaccination by simply providing people with more facts.<sup>28</sup> Because knowledge acquisition is a social process, the response to medical and other scientific information will always be shaped by social structures and interactions. Until the government adopts and implements policies that attack material inequality and unfair treatment across several domains (housing, medical care, education, criminal justice, and so on), it is unreasonable to expect or request greater trust and community-oriented thinking on behalf of people who have been exploited. Trust and reciprocity are inseparable.

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