

# Vaccine Hesitancy: An Extremely Dangerous Decision

by  
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## Foreword by

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# ***Vaccine Hesitancy: An Extremely Dangerous Decision***

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# Foreword

History, if recorded and told truthfully, helps us to not repeat the past and can serve as a guide to a better future. In 1905, George Santayana wrote, “Those who cannot remember the past are condemned to repeat it.” These are powerful words and are just as relevant in today’s world. It is concerning when I see efforts working to keep the history about racism, social injustice, and inequality skewed and obscured.

***Vaccine Hesitancy: An Extremely Dangerous Decision*** is a timely and necessary handbook that carefully examines historical facts about medical and healthcare in the black and brown communities truthfully. The COVID-19 pandemic for the past three years illuminated the disparities and inequities of the present day healthcare system. However, it also provided us with a timely opportunity to remember events of the past and deconstruct myths that are misleading, harmful, and dangerous.

It is important for each of us to reflect on the myths that might have roots in medical stories told by our families and circulated within our culture. There is an individual responsibility that rests within each of us to find the truth and to spread the truth. Our personal health decisions should always be carefully considered, based on trusted advice and evidence. ***Vaccine Hesitancy: An Extremely Dangerous Decision*** is an excellent resource for students, educators, and parents for learning and discerning the histories of vaccines, COVID-19, medical and healthcare in the black and brown communities, and about the United States Public Health Service Study of Untreated Syphilis in the Negro Male (USPHSSUSNM) at Tuskegee and Macon County, Alabama, 1932 - 1972.

The question, “Why did vaccine hesitancy become such a challenge in the African American community,” touches me deeply and personally. My father, Freddie Lee Tyson, was one of the 623 beloved human beings unwittingly used as a subject in the unethical USPHSSUSNM. Due to numerous misconceptions and myths concerning the study, many African Americans refer back to it as a reason for not getting vaccinated or participating, or for participating in biomedical research that will benefit us all.

The Voices for Our Fathers Legacy Foundation, formed by descendants of the African American men in the USPHSSUSNM experiment, is adamant that no one ever use this study as the reason for not getting vaccinated. Vaccines can be life savers for your loved ones, for your friends, and for you. The men in the study were never told or consented to being a part of the longest nontherapeutic biomedical study in U.S. medical history. They were denied lifesaving treatment that could have been made available to them and their families! We should never deny ourselves nor be denied the best medical and health treatment available.

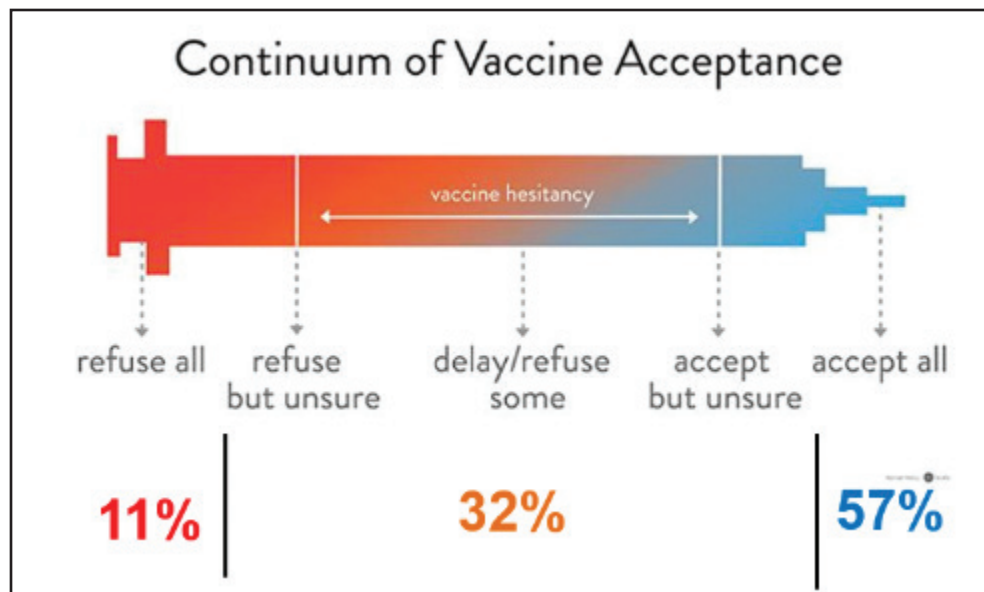
A special thanks to neuroscientist Kenneth Wesson for the insights and wisdom he shared throughout this book. Thanks also, to the California State Association of African American Superintendents and Administrators for bringing together Education, History, and Health. Education cannot exist without good health; and good health cannot exist without good education. Our history can never be forgotten if we hope for a bright future for the African American community.

*Ms. Lillie Tyson Head, President*  
*Voices for Our Fathers Legacy Foundation*  
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## Introduction

As we responded to the initial outbreak of COVID-19, we quickly adapted to sudden school closures, to working from home, and the strange new practice of “sheltering in place.” Almost instantly, we grew accustomed to the new COVID-19 health and hygiene protocols – carrying hand sanitizers, disinfecting door knobs and shopping cart handles, social distancing, and minimizing any in-person contact whether social or work-related. That included our extended families, in-laws, and close relatives. Also new to the experience was the prospect of a series of regularly scheduled vaccinations for a new pandemic caused by an unheard of disease that came with myths of its origins as well as fictitious stories concerning effective remedies.

At any point in time, individuals who are vaccinated vs. those who are unvaccinated have traditionally fallen into two distinct outcomes-based groups. Equally important, among the ranks of the unvaccinated are further subdivisions. This wide range stretches between those who have yet to receive *both* COVID-19 vaccines as well as *both* booster shots to those who refuse to get a single shot of either type. Unfortunately, to the coronavirus, there is no distinction to be made between a “hesitant unvaccinated individual” and another who refuses to take any vaccination at all. Vaccine behaviors can be positioned along the Continuum of Vaccine Acceptance developed at the John Hopkins Coronavirus Resource Center presented below.



To the far left of the spectrum are individuals representing 11% of the population who have not received a single COVID-19 vaccine and have no intentions of ever doing so. Most Americans (57%) can be found at the opposite end of the acceptance continuum and have taken each of the available shots and boosters. They are considered “up to date.” Those individuals who fall in the middle of the continuum are still “hesitating, delaying, or are unsure” about taking one or more of the recommended vaccines. They are the individuals for whom this information has been painstakingly collected -- the “vaccine hesitant,” are also referred to as the “movable middle.” For them, we have painstakingly assembled and laid out the facts worthy of consideration to help them move from that middle of the continuum to the “accept all” position where they (and those close to them) will be safest from the life-threatening effects of COVID-19.

Over the past three years, we have been inundated globally with information, with pleas from medical experts, and with evidence-based news reports on the coronavirus and how to avoid it. However, there are those who are yet to receive any of the recommended COVID-19 vaccinations. They are unlikely candidates for change who can be pushed towards the vaccines by new facts, statistics, or the research information. Unfortunately, the “refuse all” group is unmoved by the fact that they are

jeopardizing the lives of their loved ones, friends, family members, as well as anyone who enters their social constellation no matter how briefly, where they may be exposed to the coronavirus with life-threatening consequences. While this information may help them, they must be willing to read it and accept it. Instead, this handbook on vaccine hesitancy has been assembled for easy understanding by members of the movable middle.

A December 2022 Commonwealth Fund study reported that COVID-19 vaccines have prevented more than 18.5 million hospitalizations and 3.2 million deaths in the U.S. saving our country approximately \$1.15 trillion.<sup>1</sup> A distinguished professor at the CUNY Graduate School of Public Health & Health Policy, Luisa Borrell, summed up the COVID-19 equation concisely in an August 2021 article published in the New York Times. In her article, “They Don’t Want the Shot. They Don’t Want Colleagues to Know,” she writes, “The more people who are out there without the vaccine, the more COVID will spread.” Significantly reducing vaccine hesitancy has the potential to save lives, money, and a tremendous amount of grief.

Vaccine hesitancy in the African American community is based in part on a suspicion that the scientists behind developing COVID-19 vaccines did not have the best interest of Black people in mind. In truth, though, behind the vaccines are those like Dr. Kizzmekia Corbett, is a Senior Research Fellow working in the Viral Pathogenesis Laboratory at the National Institute of Allergy and Infectious Diseases (NIAID).



*Dr. Kizzmekia Corbett received her PhD in microbiology and immunology from the University of North Carolina, Chapel Hill. She played a major role in developing one of the two COVID-19 vaccines that became available.*

Dr. Corbett is an African American scientist, who played a key leadership role in the development of one of the two COVID-19 vaccines that was initially approved for use in the United States. Dr. Corbett and Dr. Barney Graham led the team of scientists that developed the lifesaving coronavirus vaccine. Their team worked with the pharmaceutical company, Moderna, to create one of the two mRNA vaccines for COVID-19 currently available in the United States.

## ***Our Goals***

Contrary to pronouncements seen on social media and by politicians, the coronavirus is not a hoax. It is a “real virus,” and should be taken “real seriously” by every child, teenager, and adult in every neighborhood, city, and state. The goals of this handbook are the following:

1. To empower young African American teens and young adults to make well-informed decisions about vaccinations and vaccine hesitancy. We do this by equipping them with a wealth of information on COVID-19 and how it spreads, as well as the importance of disease prevention by getting vaccinated and making sure that people within their constellation are also fully vaccinated.
2. To address the general concerns that some in the African American community have had for decades regarding government-sponsored health recommendations. One key source of mistrust resulted from the “*United States Public Health Service Study of Untreated Syphilis in Negro Males*” (USPHSSUSNM -- a.k.a., “The Study of the Long Term Effects of Untreated Syphilis”).
3. To give youth, young adults, families, and educators the latest, most reliable, and culturally-focused information on how to curtail the spread of COVID-19 in the black community. We encourage you to share this information with family members and peers of all ages.

The target audience of this informational handbook is:

- Middle and high school students
- Teachers and school administrators for middle school and high school students (and some higher education institutions)
- Parents, caregivers, and community leaders.

## **The Three Driving Questions**

“***Vaccine Hesitancy: An Extremely Dangerous Decision***” has been organized around the three key questions that students, parents, and educators of color should be asking (and seeking the answers to) about vaccine hesitancy and COVID-19 vaccinations. Author James Thurber once said, “It is better to know *some* of the questions than *all* of the answers.”



The three focus questions that we will be posing and providing answers to include:

1. ***What exactly is vaccine hesitancy?***
2. ***Why has vaccine hesitancy remained such a challenge to the American community?***
3. ***How can we reduce vaccine hesitancy among our peers, friends, and family members in the African American community?***



In the process of answering these key questions, several other sub-questions naturally surfaced. Those questions have been anticipated and are both presented and answered for the reader as well.

### **How and where was COVID-19 discovered?**

Before we can address vaccine hesitancy, it will be useful to discuss some of what we know today about COVID-19 . The coronavirus is a serious illness caused by a virus called SARS-CoV-2. People with severe heart or lung conditions are at a high risk of developing serious complications from the COVID-19 illness, as well as people with ongoing medical conditions like diabetes (which is prevalent in the African American community). The name for this novel disease was “coronavirus disease 2019,” which was condensed into “COVID-19 ,” by taking the following:

Corona = **CO**  
Virus = **VI**  
Disease = **D**  
2019 = **'19**

Combined they gave us **CO-V-ID-19** or **COVID-19**.

There are key dates and events between the years 2019 and 2021 on the COVID-19 timeline. Some of those dates appear on the CDC website. They have been condensed and are presented below.

- ***December 12, 2019***

Several patients in China’s Hubei Province begin experiencing symptoms of a strange pneumonia-like illness that does not respond to standard treatments.

- ***December 31, 2019***

The “World Health Organization Country Office” in China is informed of several cases of a mysterious pneumonia of unknown etiology (cause) with symptoms that include shortness of breath and fever (in Wuhan, China). All initial cases seemed to be connected to the “Huanan Seafood Wholesale Market.”

- ***January 7, 2020***

Public health officials in China identify a novel coronavirus as the causative agent of the unexplained outbreak.

- ***January 13, 2020***

The Thailand Ministry of Public Health confirms the first confirmed case of the SARS-CoV-2 virus *outside* of China.

- ***January 19, 2020***

Worldwide, 282 confirmed cases of this 2019 Novel Coronavirus have been reported in four countries in the same general region (China, Thailand, Japan, and the Republic of Korea).

- ***January 20, 2020***

The CDC reports the 1<sup>st</sup> case of the 2019 Novel Coronavirus in the U.S.

- ***January 24, 2020***

The CDC confirms a travel-related infection of the SARS-CoV-2 virus in the United States (Illinois), bringing the number of cases in the U.S. to two.

- ***January 27, 2020***

The U.S. Food and Drug Administration (FDA) announces that it will take “critical actions” to develop a coronavirus vaccine with interagency partners, including the CDC.

- **February 3, 2020**

The U.S. Department of Homeland Security (DHS) directs all flights from China and all passengers who have traveled to China within the last 14 days to be routed through one of eleven airports in the U.S. for enhanced screening procedures and a possible 14-day quarantine.

- **February 10, 2020**

Worldwide deaths from the 2019 Novel Coronavirus reach 1,013 cases. The SARS-CoV-2 virus has killed more people than the severe acute respiratory syndrome (SARS-CoV-1) outbreak, which claimed 774 lives globally from November 2002 to July 2003.

- **February 11, 2020**

The World Health Organization (WHO) announces the official name of the disease as “COVID-19,” an abbreviated form of “Coronavirus Disease 2019.”

- **February 23, 2020**

Italy becomes a global, non-Asian, COVID-19 hotspot. The government effectively locks down most of the country.

- **February 25, 2020**

The CDC’s Dr. Nancy Messonnier braces the U.S. for new mitigation efforts to contain the SARS-CoV-2 virus including possible school closings, workplace shutdowns, and canceling large public events referred to as “super spreader” venues.

- **February 29, 2020**

The CDC and the Washington Department of Public Health report the first death of an individual in a confirmed case of COVID-19 in the U.S.

- **March 11, 2020**

After more than 118,000 cases in 114 countries and 4,291 deaths, the WHO declares COVID-19 a global pandemic.

- **March 13, 2020**

More than 5.7 million California students begin learning remotely from home. Entire school districts close to minimize the spread of the coronavirus. Most of the state’s 1,000+ school districts anticipate shutting down for two to four weeks. “This is a temporary thing,” said Christine K. Johnson, a professor of epidemiology at UC Davis. “If we do it well, we can manage this outbreak and continue to keep cases low.”

At least seven other states — Oregon, West Virginia, New Mexico, Michigan, Ohio, Kentucky and Maryland — order all public schools to shut down. More than 32 million American students have been affected by coronavirus-related closures, according to a tally by Education Week.

Two major educational problems surface: About 60% of CA students rely on going to schools for their meals. Schools also begin to struggle with bandwidth issues required to support remote learning. Communities impacted by poverty are now also impacted by massive technology deficiencies.

- **March 15, 2020**

States begin to implement widespread shutdowns (businesses, restaurants, schools, etc.) to prevent the spread of COVID-19. The state of Ohio calls for restaurants and bars to close.

This was not our first national shutdown due to a rapidly-spreading disease. The first took place in 1918 because of the “Spanish Flu” epidemic.

- **March 19, 2020**

“Sheltering in Place” and “Social Distancing” become new terms in our everyday vocabulary.

California's governor issues a statewide stay-at-home order, shutting down all but essential businesses and instructing residents to leave their homes only when necessary.

- **April 6, 2020**

Hundreds of doctors and civil rights groups urge the CDC and the U.S. government to release race and ethnicity data on COVID-19 case numbers in order to reveal the impact that the virus is having on communities of color.

- **April 7, 2020**

The Chicago Tribune reports that Black people account for 68% of the COVID-19 related deaths, despite being only 30% of the total population. They are dying at a rate nearly 6 times greater than White Chicagoans, who account for around 33% of the population, and only 14% of the deaths. These numbers highlighted many of the often mentioned health disparities in the U.S.

- **April 13, 2020**

At a White House press briefing, President Trump announces that the U.S. will stop contributing funds to the WHO, shocking the global public health community. Few could find any rational basis for the action.

- **April 28, 2020**

Polls show that many people in the U.S., particularly those ages under 30 years or making less than \$40,000 per year, plan to defer medical care for the coronavirus, because of (1) the cost of treatment due to the lack of insurance, or (2) being under-insured or uninsured, potentially leading to a larger spread of COVID-19 .

- **April 30, 2020**

Since mid-March 2020, more than 26.5 million people in the U.S. have filed for unemployment, which also increased the number of people without health insurance during this pandemic.

- **May 19, 2022**

The United States officially surpasses the one million mark for known deaths from COVID-19, with millions more mourning the losses of spouses, parents, children, siblings, friends, and colleagues.

- **July 31, 2021**

An average of 652,000 doses of the COVID vaccine are administered daily, according to the CDC.

## **When you get COVID, what happens?**

While a sore throat has always been a symptom of the coronavirus, experts found that the COVID infections were becoming more common, and more dangerous, especially with the Omicron strain of COVID, which became dominant in the U.S. Individuals who have contracted COVID-19 show a wide range of symptoms ranging from mild flu-like warning signs to severe illness. Symptoms may appear 2-14 days after one's first exposure to the coronavirus. Anyone can have mild to severe symptoms, but the more severe symptoms are clearly more dangerous or deadly.

The possible symptoms include the following:

- Fever and/or chills
- Shortness of breath
- Difficulty breathing
- Fatigue
- Cough
- Aching muscles

- Body aches
- Headaches
- Sore throat
- Congestion and/or runny nose
- Nausea or vomiting
- Diarrhea

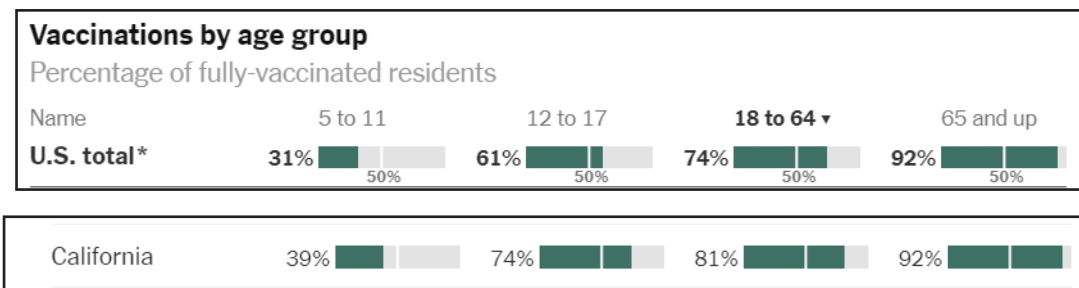
The symptoms above are not intended to represent an exhaustive list of all possible coronavirus symptoms. The list of warning signs will likely change with new variants of the coronavirus and may also vary depending on one’s vaccination status, which is why the continuum of vaccine acceptance can be a predictor of health outcomes.

One of the more alarming aspects of COVID-19 is that there are numerous lingering medical issues connected to the infection. One study by eClinicalMedicine (part of THE LANCET Discovery Science, a patient-led research group) linked over 203 symptoms to the coronavirus, all of varying severity and duration.

According to Maya N. Clark-Cutaia from the New York University Meyers College of Nursing, it is vaccinated patients with the Delta strain or the original coronavirus who tended to show symptoms of headaches, congestion, and sinus problems, all of which seem like a very bad cold, but unvaccinated individuals are more likely to experience shortness of breath, coughing and other flu-like symptoms.

Months after the symptoms of COVID-19 go away, an estimated 10-30% of coronavirus sufferers report persistent or new symptoms. This is referred to as “long COVID,” where people experience long-term debilitating symptoms including fatigue, shortness of breath, erratic heart rates, headaches, dizziness, depression, and memory/concentration challenges.

### ***Who is getting infected by age group?***



According to the experts, if your home tests indicate negative results for COVID, but you still have some COVID-like symptoms, it may be a positive sign that you have been exposed to the coronavirus, but your immune system has successfully defeated the virus (or you have something else, but not COVID-19). In either case, you should wear a mask, avoid large crowds, and closed spaces, and keep away from others until you have fully recovered.

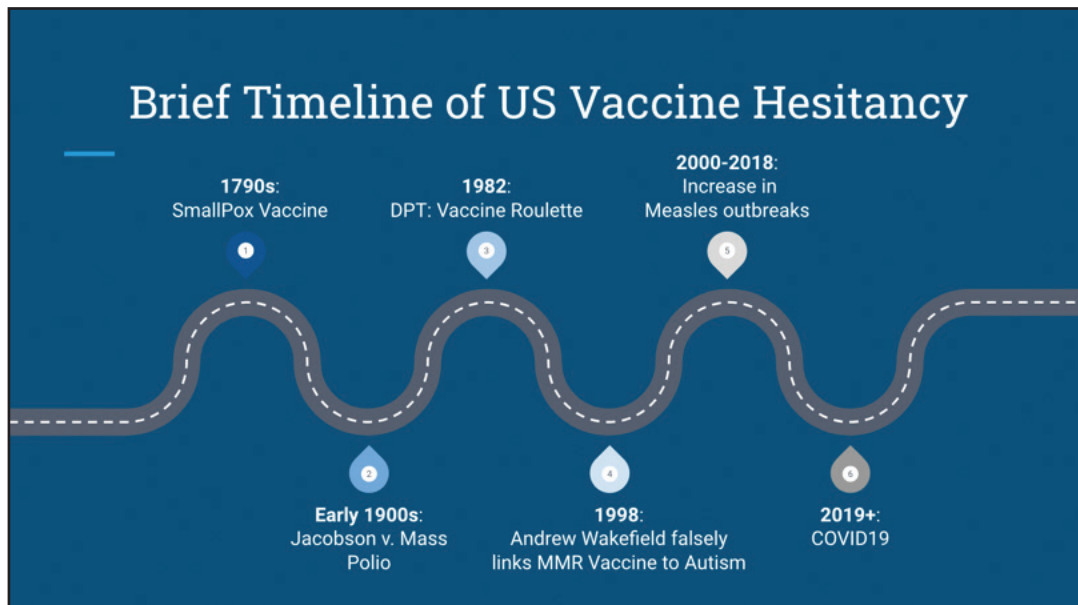
### ***A Brief Overview of vaccinations:***

Over the past seven centuries, vaccinations have become one of the most successful public health interventions in history. For centuries, it was quite common for epidemics to wipe out 50-100% of an entire village or tribe in a short time. During the 15<sup>th</sup> century, people in different locations throughout the world discovered that smallpox illnesses could be prevented by intentionally exposing healthy individuals to the disease.

In the late 1700s, Dr. Edward Jenner, an English physician, discovered that people who had been infected with cowpox earlier were by some strange means immune from contracting smallpox. Subsequently, Jenner set about an experiment where he exposed a few healthy individuals with

matter from a human smallpox sore, and they became immune from the disease. (The Latin word for cow is “vacca,” from which the new term “vaccine” was coined.)<sup>2</sup>

With the global availability of vaccines, smallpox has been eradicated throughout the world and endemics of polio, measles, rubella, and congenital rubella syndrome have largely been eradicated in both North and South America.



It will be difficult to continue this conversation without defining several central terms - vaccine, vaccine hesitancy, and herd immunity.

A **vaccine** is typically a fluid substance that is injected into the body to stimulate the body’s immune system to fight against a specific disease. It is usually administered through needle injections, although some are administered by mouth or nasal sprays. Vaccines work by mimicking an infectious agent like viruses, bacteria or other microorganisms (referred to as “**pathogens**”) that can cause a disease. This, in a sense, “instructs” our immune system on how to rapidly and effectively defend against the virus.<sup>3</sup>

Vaccines prompt your immune system to produce its own natural protection, just like a natural infection would. A vaccine works with your immune system so your body will know how to fight the disease if you are exposed to it again.<sup>4</sup> Getting vaccinated protects you against all forms of COVID. In the beginning, it protects you against the mild, moderate, and severe cases. Then, for the next 3-5 months, the COVID-19 vaccine will protect you against moderate to severe COVID.

According to WHO, most COVID-19 vaccines wear down somewhere in the neighborhood of 4-6 months, requiring a booster shot to strengthen a person’s protection against reinfection. Doing so provides a massive “boost” in antibody levels and creates an almost impenetrable immunity “shield” against the coronavirus and possibly its variants.

**Vaccine hesitancy** is a temporary or permanent state of mind that produces uncertainty about making a decision “to be, or not to be” vaccinated. It shows itself as a delay in acceptance or a complete refusal to get vaccinated despite being eligible for the vaccine and the availability of vaccinations.

Much of today’s hesitancy has been amplified by digital media platforms. Vaccine hesitancy is considered an “attitude,” while the vaccination itself is an “action.” Some vaccine hesitancy can be traced back to a specific vaccination program in the past, including the now-debunked misinformation alleging that the MMR vaccine would cause autism.

Virologists (the doctors whose job it is to research, diagnose, and oversee infectious diseases), say

that once 90% or more of a population (children and adults) have been fully vaccinated, a region or country has reached the elusive **herd immunity**. Once they have reached that threshold, they are highly resistant from that point forward to spread the disease. Either a high percentage of individuals have been previously infected, or they have been vaccinated, achieving herd immunity for the regional population. While there is an urgent need to vaccinate all Americans, reaching herd immunity is our second best alternative.

When someone is vaccinated, they are very likely to be protected against the target disease, but not everyone can be vaccinated. People with health conditions that have weakened their immune systems (such as cancer or HIV) may not be able to get vaccinated. These people can still enjoy some protection if they live among people who are vaccinated, since the pathogen will have a hard time circulating because most of the people it encounters are immune (or masked). Thus, the more people vaccinated, the less that people who are unable to protect themselves from vaccines are at risk. It is estimated that 70-90% of Americans will need to be vaccinated for us to reach herd immunity, but vaccine hesitancy threatens our chances of reaching this target. As each person is vaccinated, we get one step closer to herd immunity and returning to “normal” life.

For decades, U.S. servicemen have routinely lined up, rolled up their sleeves, took their shots, got their vaccination card stamped, and returned to their barracks. During World War I, soldiers found themselves in the freezing, muddy, and rat-infested trenches, perfect conditions for spreading disease. Infectious diseases thrived during a war where there were (1) unsanitary conditions, and (2) men in very close and constant person-to-person contact. The 1918 flu pandemic and the war combined for a deadly alliance against most soldiers. The Smithsonian Institute reported that over 670,000 Americans died from the 1918 flu pandemic, when no vaccine was available.

Fortunately, the soldiers were vaccinated against smallpox, cholera, and typhoid before they were deployed overseas. Unfortunately, there was no vaccine yet for influenza which killed between 20-50 million people worldwide (some estimates ran as high as 100 million), and killed more US troops during World War I than combat battles did. The “Spanish Flu” pandemic killed 1 in 67 (over 45,000) U.S. soldiers during the war, subsequently making a vaccine for the flu a national priority. However, it was not until 1945 that a vaccine for the flu was available to military personnel, and in 1946 a flu vaccine was approved for civilian use.

Today, most people throughout the world have access to routine vaccinations that are taken over the course of several years beginning in infancy, which is why we don’t remember many of the diseases or vaccines. More importantly, nearly every child in the U.S. has been vaccinated, so most parents have nearly forgotten that the diseases, now prevented by vaccines, even exist today.

During annual checkups, our primary care physicians (PCPs) will often tell us that we are due for another inoculation that will protect us from one of the illnesses below:

- polio
- tetanus
- influenza (flu)
- hepatitis B
- hepatitis A
- rubella
- Hib
- measles
- whooping cough
- pneumococcal disease
- rotavirus
- mumps

- chickenpox
- diphtheria
- HPV
- meningococcal disease.

In 1971, the measles vaccine was combined with the vaccine against the mumps and rubella into a single new vaccine called MMR. Over 90% of American parents indicate that they regularly keep up with their child's schedule of recommended childhood vaccines such as MMR. However, 9% say they have delayed or skipped some of those vaccines.

Among those "hesitant" parents, 69% have not gotten a COVID-19 vaccine themselves, including 64% who fall into the "refusal" vaccines category. Unfortunately, many people who have previously received their own childhood vaccines and accepted other vaccines in the past, are less-than-rational about COVID-19 vaccinations for themselves or for their children.

### **The Clinical Trials for COVID-19 Vaccines**

Today, medical studies are conducted quite differently than in years past. In a contemporary scientific or medical study (often referred to as a "trial" in science, and a "clinical trial" in medicine), there are typically two groups of individuals who are compared at the end of the experiment.

1. The "experimental group" or the "treatment group" receives the medication (the treatment) that the researcher is interested in determining whether or not it is effective.
2. A "control group" receives either no treatment at all or they are given a treatment that appears to be identical (or at least similar to) whatever the treatment group is receiving. However, it is known in advance that there will be no effect from the "fake treatment" that the control group receives, which is called a "placebo" -- an inactive substance that looks and feels like the drug, pill, or shot that was given to subjects in the experimental group. This procedure eliminates what is known in experimental circles as "the placebo effect," which is a phenomenon that occurs when a patient's condition improves because he/she "believes" they have been administered an effective treatment. The mind stimulates healing in the body, as patients convince themselves that they should be getting better from the placebo pill, and respond by actually getting better physically.

Vaccines save 2 to 3 million lives annually, according to data from UNICEF, constituting one of the greatest advances in modern medicine. With the outbreak of COVID, there was a global effort to find a cure quickly. Although the COVID-19 vaccines were developed as rapidly as possible, they still went through meticulous safety procedures and clinical trials to assure that the vaccines would meet the standards for (a) safety and, (b) effectiveness, allowing the vaccines to be used under appropriate conditions anywhere in the entire world. To date, COVID-19 vaccines have been safely used to vaccinate billions of people worldwide.

On December 14, 2020, Sandra Lindsay, an African American critical-care nurse in New York, became the first person in the United States to receive a COVID-19 vaccine outside of the clinical trials. One of the often-cited hesitation fears in the African American community has been that the COVID vaccine may have been properly tested, but it was not tested on African Americans, which is also not an accurate statement.

Researchers made certain that the clinical trial participants for the vaccines were approximately as diverse as the American population. The trials for the first two COVID-19 vaccines included:

- 10% Black participants

- 20% Latinx
- 25% of the people were in the older age groups, and included high risk people with compromising medical conditions (obesity, diabetes, and heart and respiratory conditions.)

The U.S. study participants for the “one-shot COVID-19 vaccine” included:

- 15% Latinx or Hispanic
- 13% Black or African American
- 6% Asian American
- 1% Native American

In the Pfizer COVID-19 vaccine tests, their participants’ list included:

- 10% Black or African American (approximately 4,000)
- 26% Latinx (approximately 11,000)
- 5% were Asian American
- 46% were individuals aged 56 or older. .

Moderna recruited over 30,000 subjects for their trials including:<sup>5</sup>

- 10% who were African Americans
- 20% who were Latinx or Hispanic
- 5% were Asian American
- 25% age 65 and over.

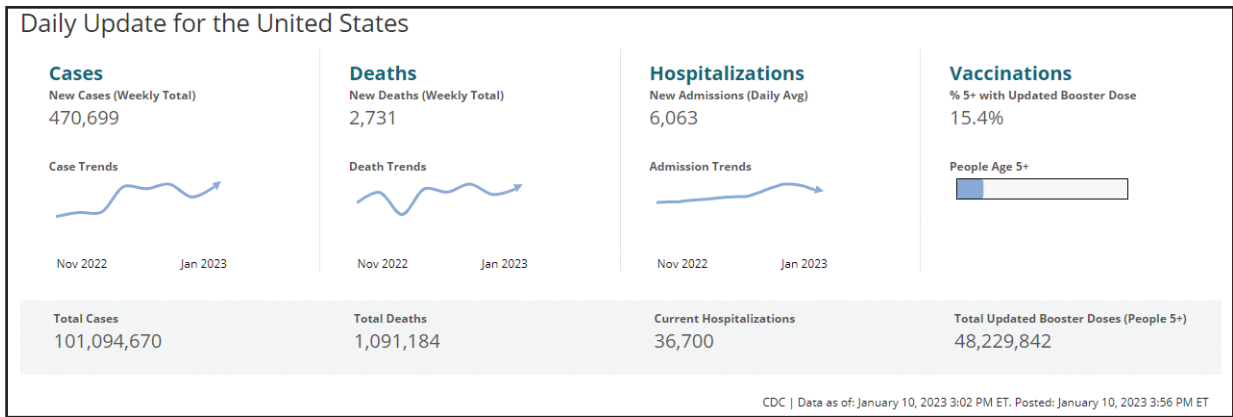
Despite the devastating impact that COVID-19 has had on the people in the African American community, medical researchers encountered difficulties in trying to include 3,000 African American participants in the first two large clinical trials of a COVID-19 vaccines. The haunting history of being “America’s guinea pigs” remained fresh in the minds of many Black Americans who struggled to make vaccine research participant decisions. Consequently, most clinical trials had 10% Black representation, although the overall population of African Americans in the US is closer to 13%, making Blacks slightly underrepresented in these trials.

In the future, it is hoped that participation will reflect the percentages of people found in each ethnic group living in the U.S., since *illnesses, disease, and pandemics do not discriminate by race. Unfortunately*, in all federally funded research, African Americans participate less often than White Americans across a wide range of studies. It is not uncommon for research studies to also have restrictive “inclusion criteria” that eliminates Blacks from the participant pool. Nonetheless, experienced researchers should continue looking for ways to modify restrictions, which would allow more Black subjects to participate in clinical trials. Doing so will likely lead to more effective pharmaceutical products.

According to the Centers for Disease Control and Prevention, as of January 2023 (see “Daily Update for the United States” chart below), there have been:

- 101,518, 229 reported cases of COVID in the U.S. (and likely tens of thousands more that went undiagnosed, underreported, and unreported)
- 1,095,149 American deaths (directly attributed to COVID-19 )
- 49.5 million booster doses administered throughout the US
- 32,348 current hospitalizations as of January 2023
- 98,398 COVID deaths in California as of this same date

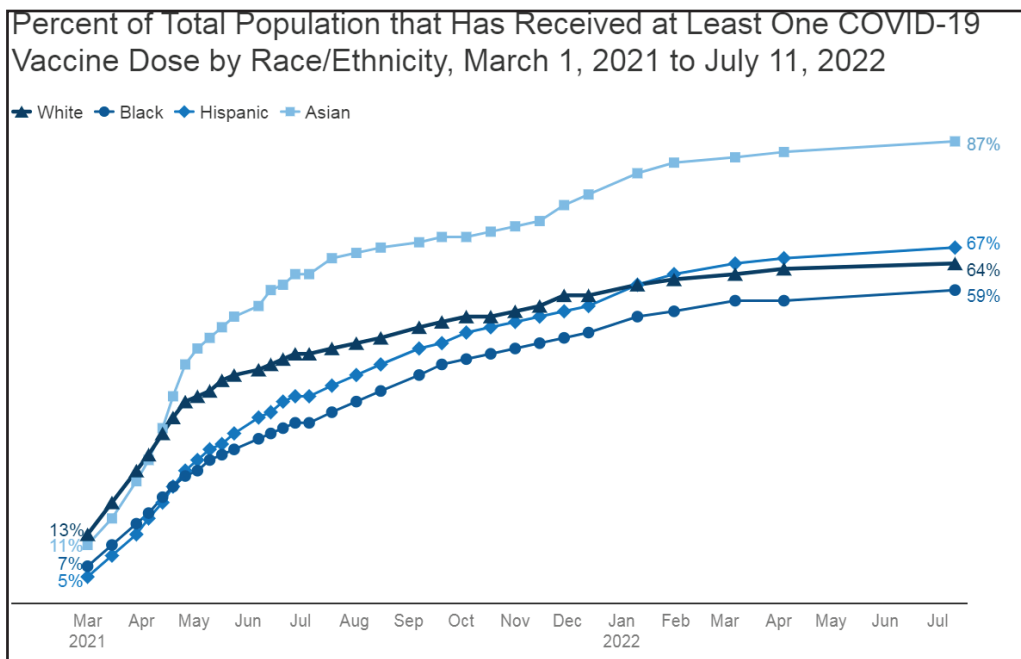




## **COVID-19 statistics by race:**

The United States has a higher rate of infection than many other wealthy country does, and the pathogen has continued to spread in a large population affected by inequity, political divisions, a sometimes an overwhelmed public health system, and an inconsistent assortment of policies state-by-state.

The CDC chart below is a graphic representation showing the percent of the U.S. population (by race) that has had at least *one* COVID-19 vaccine. Recognizing their accessibility to a second shot as well as two boosters, some of these individuals likely would still fall into the “hesitant” group since they have not been “fully vaccinated” (two vaccines and two booster shots).

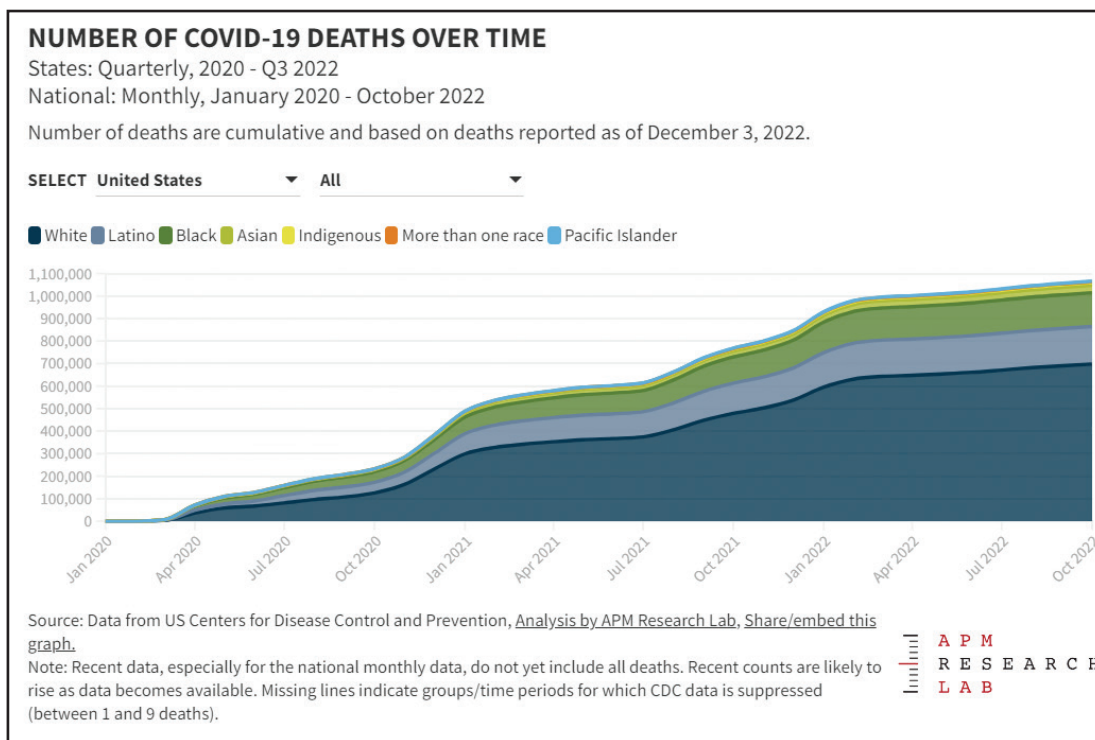


- As of July 2020 (an early stage in the pandemic):
  - Latinx people were 5 times more likely to die from COVID than White Americans.
  - AIAN (American Indian and Alaska Natives) and Blacks were about 3-4 three times more likely to die than White Americans.
  - Asian Americans had the same risk of COVID death as White Americans.
- The overall vaccination rate across states for Asian Americans was higher compared to White people (87% vs. 64%),
- Blacks make up only 8% of people who have received booster shots.
- Between Winter 2022 and June 2022, infection rates had fallen across all groups.

- In April 2022, Asian Americans had the highest infection rate.
- Also that month, Black, AIAN (American Indian and Alaska natives), and Latinx groups had the lowest infection rate, marking it the first time these patterns were observed since the start of the pandemic, suggesting that these groups are, gradually but steadily, moving towards the “fully vaccinated” category.

### Lives lost to date:

- 150,593 Black Americans are known to have lost their lives to COVID-19 through December 3, 2022. There were 755 new deaths reported among Black Americans for the last full month of data (October 2022), which is a 24% decrease from deaths in the preceding month (999).
- Nationwide, Black Americans have experienced 14% of all reported COVID-19 deaths (but represent only 12.6% of the population.)
- Data show Black Americans are (a) 10% more likely to contract COVID-19 than White Americans, (b) 3 times more likely to be hospitalized, and (c) twice as likely to die.
- 704,529 white Americans are known to have lost their lives to COVID-19 through December 3, 2022. There were 7,650 new deaths reported among white Americans for the last full month of data (October 2022), which is an 11% decrease from the preceding month (8,612).
- Nationwide, white Americans have experienced 65.4% of all deaths, while they represent 59.7% of the population. (See “Who are the unvaccinated?”)

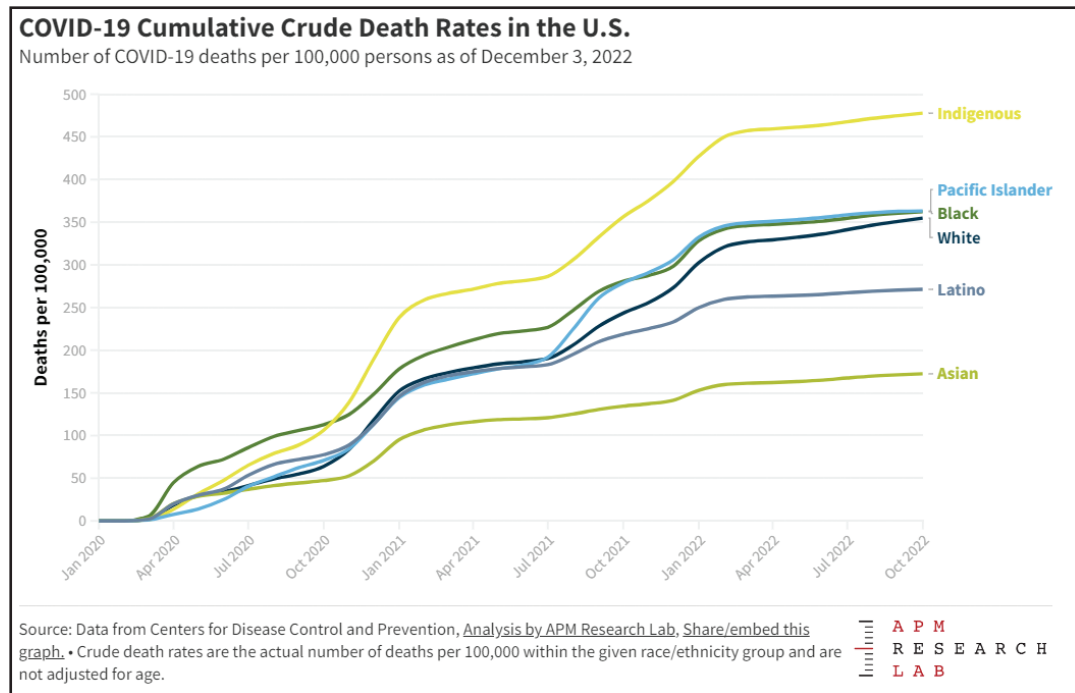


In the summer of 2020, Blacks, AIANs, and Latinx people experienced higher rates of death than White Americans<sup>6</sup>. COVID wards filled up quickly. In many hospitals there were no beds available to treat the large numbers of unvaccinated patients being admitted with coronavirus symptoms.

### The Basic Mortality Rates

For every 100,000 African Americans, approximately 365 have died from COVID-19 . This is slightly more than twice the rate of Asian Americans, who have had the lowest rate, and about 25% less than Indigenous Americans, who have the highest rate.<sup>7</sup>

One unstated problem is that generations of Black and Latinx/Latin Americans and other communities of color are overrepresented in severe COVID-19 cases as a consequence of inequities in the US. People of color are vulnerable to many of the COVID-19 risk factors. One of them is being an essential worker on the front lines of the battle against COVID-19. Black and Brown people are more likely to be working in front-line, essential jobs that cannot be performed at home in front of a computer. They are often in “human-facing” occupations. Needless to say, their exposure increases the chances of being infected by the coronavirus.



Estimates are that at least 496,000 more people died last year during the coronavirus pandemic than the official COVID-19 death counts report shows, giving us an incomplete account of the actual death toll of the pandemic. There are many people who could not be treated in overcrowded hospitals, and thousands of others for whom hospital treatment was too late. Others had no health insurance and did not go to hospitals because they were afraid of the high costs of hospital care and the subsequent financial burden.

Total cumulative data show Black, Latinx, American Indian or Alaska Native (AIAN), and Native Hawaiian or Other Pacific Islander (NHOPI) people have experienced higher rates of COVID-19 cases and deaths compared to White people when data are adjusted to account for differences in age by race.

## **Question #1:**

### ***What Exactly Is Vaccine Hesitancy?***

Although people of color have been overrepresented in COVID-19 infections and deaths, vaccine hesitancy in our groups has fueled the crisis. The “vaccine hesitant” are people with fears that they sincerely believe are legitimate.

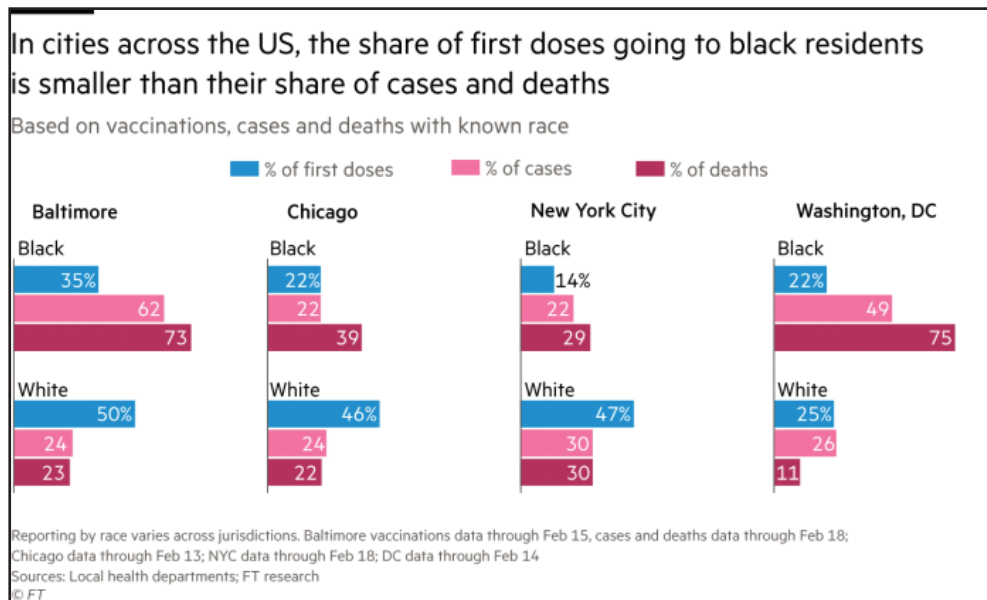
The World Health Organization describes *vaccine hesitancy* as a “delay in acceptance or refusal of vaccines despite the availability of vaccination services.” Most vaccine-hesitant people are not “crazy anti-vaxxers,” but are the individuals who you would find in the middle of the continuum of vaccine acceptance. They also tend to “under-immunize” (for various reasons) their children rather than not immunizing them at all.

The primary reasons for their hesitancy, as reported by the National Library of Medicine, fall into 3 general groups (the three C's):

1. Some merely feel a lack of **confidence** in (a) the vaccines' effectiveness, (b) the safety of COVID vaccines, (c) the companies and systems that produced the vaccines, and/or or (d) the policy makers who were most responsible in getting the vaccines to the public.
2. Some grew **complacent** due to their perception of the "low risk" of ever contracting COVID-19.
3. Others felt that vaccinations are not **convenient**. *They perceive problems in their* availability, accessibility, the appeal of immunization services, including times, places, languages, and cultural contexts.

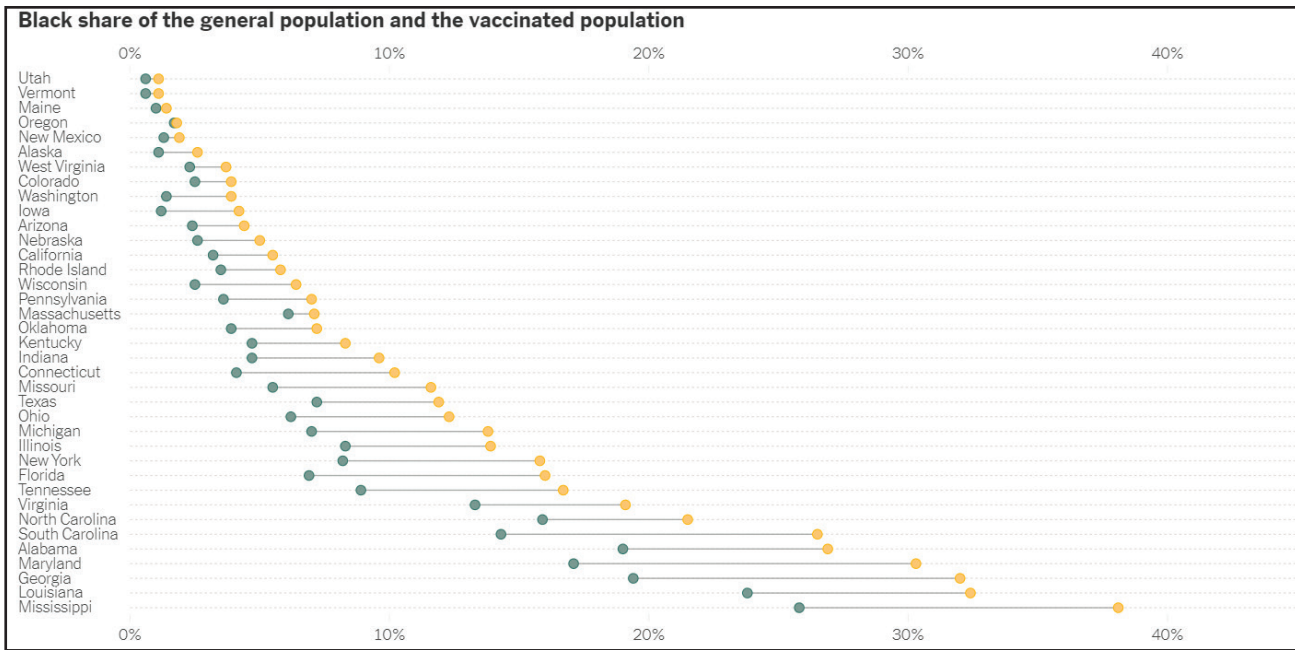
In July 2020, a Pew Research Center survey reported that only 72% of Americans said they would probably or definitely get the coronavirus vaccine when it became available. That number decreased to 54% among African Americans. A national question became, "Why do many African Americans hold such a high degree of distrust in American medicine when a COVID-19 vaccine could be a lifesaver?" We must acknowledge the particular reasons why African Americans hold firm to their doubts.

Feeding into the "anti-Black conspiracies" was the fact that the early COVID-19 vaccine distributions did not reach into Black communities, although African Americans were overrepresented in the first responder ranks, the frontline "essential workers," and reported deaths. The chart below presents one picture showing which communities (Black versus White) received the first doses of the vaccine in large cities, with a particular focus on the percentage of the population that each race represented.



And though the gap in coronavirus vaccine availability is shrinking, African Americans and Latinx Americans have received disproportionately smaller shares of the available vaccinations, making it more difficult to decrease the numbers of unvaccinated people of color.

In the chart below (*Black Share of the General Population and the Vaccinated Population*), the yellow dots indicate a state's Black population, while the blue dots represent the percent of the Black population that has been vaccinated.<sup>8</sup>



In March 2020, the State of California listed of the employment sectors comprising the “Essential Critical Infrastructure Workers,” which included the following prioritized sectors (in descending order of critical importance):

1. Health and Public Health Sector (doctors, nurses, hospital workers)
2. Emergency Services Sector (police, firemen)
3. Food and Agriculture Sector (food workers, farmers)
4. Energy Sector
5. Water and Wastewater Sector
6. Transportation and Logistics Sector (bus drivers, taxis, Uber drivers)
7. Communications and Information Technology Sector
8. Government Operations and Other Community-Based Essential Functions (educators and government workers)
9. Critical Manufacturing Sector
10. Financial Services Sector
11. Chemical Sector
12. Defense Industrial Base Sector
13. Industrial, Commercial, Residential and Sheltering Facilities and Services

While the firefighters and police officers can often have annual incomes above \$125,000 (with overtime work assignments), many other essential workers are employed in jobs that do not pay well, pay their workers slightly above or at minimum wage, and do not offer overtime with pay (e.g., school teachers). As a result, 25% of essential workers found it difficult to pay their normal household expenses during the pandemic, partially because the number of hours in their workweek was reduced. Fewer hours = less take-home pay. Many hourly-wage earners in the fast food industry (McDonald’s, Carl’s Jr., etc.) were temporarily or permanently laid off from work. In addition to being overrepresented in the COVID-19 hospitalizations and death count, African Americans found the pandemic to be potentially disastrous for their families financially. Black and Brown Americans became overrepresented in the people who had recently lost employment (along with partial or full medical insurance).








### **Who are the Vaccinated and Unvaccinated?**

Market segmentation is a business approach used to dissect the customer population into separate groups that help industries better understand (a) what categories of people are found in the marketplace, and (b) how should these different segments of the market should be most effectively approached to maximize the sales of a company's goods or service.

In a 2021 report, Surgo Ventures divided people into five distinct “psycho-behavioral” segments that reflected “behavioral personas” in the U.S. based on vaccination behaviors, beliefs, and inclinations.<sup>9</sup> Doing so allowed health officials to craft their COVID-19 vaccination messages appropriately for each target audience recognizing that one message does not fit all vaccination behavior intentions. Their five categories included the following:

1. The **Enthusiasts** (40% of the population) consistently eager to get vaccinated,
2. The **Watchful** (a.k.a., the “wait-and-see’s” - making up the “persuadable” 20% of the U.S. population. Under the right circumstances, they are open to be convinced to get a vaccine.)
3. The **Cost-Anxious** - 14% of the population concerned about the costs
4. The **System Distrusters** - 9% of the population
5. The **COVID Skeptics** - 17% of the population, who do not intend on getting a vaccine.

Vaccine Persona	Description
 <b>Enthusiasts</b>	People who want to get the vaccine as soon as possible. A key challenge will be ensuring that they can access the vaccine before they lose enthusiasm. Their reported vaccination likelihood (on a scale up to 10) is 9.37.
 <b>Watchful</b>	People who primarily need to see friends and peers having safe, positive vaccination experiences before they will commit. Their reported vaccination likelihood (on a scale up to 10) is 4.95.
 <b>Cost-Anxious</b>	People for whom time and financial cost are the primary barriers. Every member of this group has delayed seeing care for their health in the past due to cost regardless of insurance status. Their reported vaccination likelihood (on a scale up to 10) is 4.16.
 <b>System Distrusters</b>	People who primarily believe that people of their own race are not treated fairly by the health system. Members of this group are likely to belong to, but are not exclusively, communities of color. Their reported vaccination likelihood (on a scale up to 10) is 3.81.
 <b>COVID Skeptics</b>	People who don't believe in vaccines in general, but the primary barrier is their deeply held beliefs around COVID-19. Every person in this group believes in at least one conspiracy theory. Their reported vaccination likelihood (on a scale up to 10) is 2.34.

The research findings at Surgo Ventures revealed the following characteristics by race during their market segmentation:

### COVID Skeptics

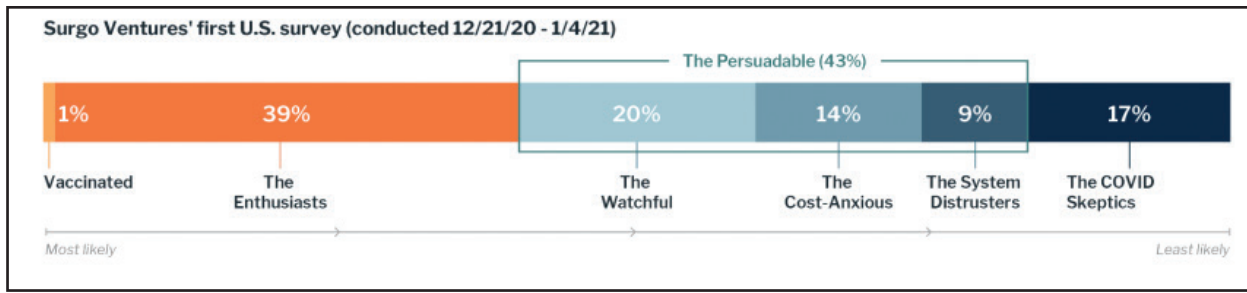
White = 17.7%  
 Latinx = 13.2%  
 Black = 10.7%  
 Republican = 61%  
 Independence = 41%  
 Democrats = 25%

### System Distrusters

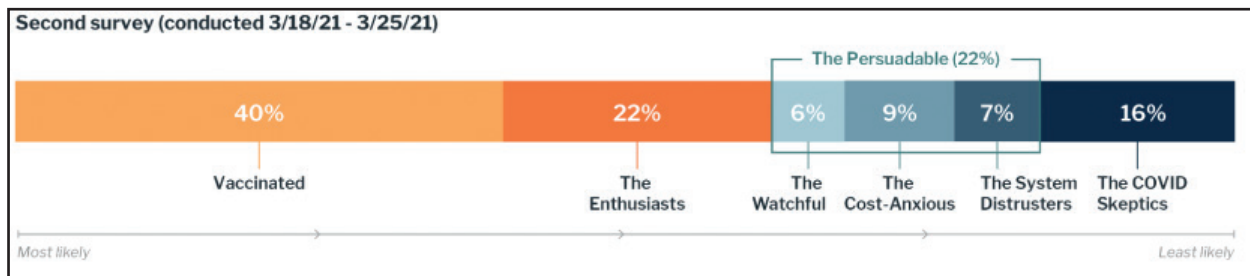
Black = 18%  
 Latinx = 11%  
 White 4%

**Enthusiasts** - 20% of respondents from across all racial and ethnic groups identified as Enthusiasts.

At the beginning of the pandemic (December 2020 to January 2021), the number of “Enthusiasts” stood at 40% (merged with those who had already been enthusiastic enough to get vaccinated).



By March 2021, the ranks of the vaccinated had swelled to 40%, and the number of Enthusiasts stood at 22% for a combined total of 62%. While the Watchful, Cost-Anxious, and the System Distrusters saw decreases in their numbers, the number of COVID Skeptics largely remained unchanged, as we have consistently seen in most of the studies where those completely rejecting any vaccination at all, reliably range from 17 to 20%. While other groups have shrunk over time, the numbers in this group largely remain stable because their minds are closed to the input of new (contradictory) information.



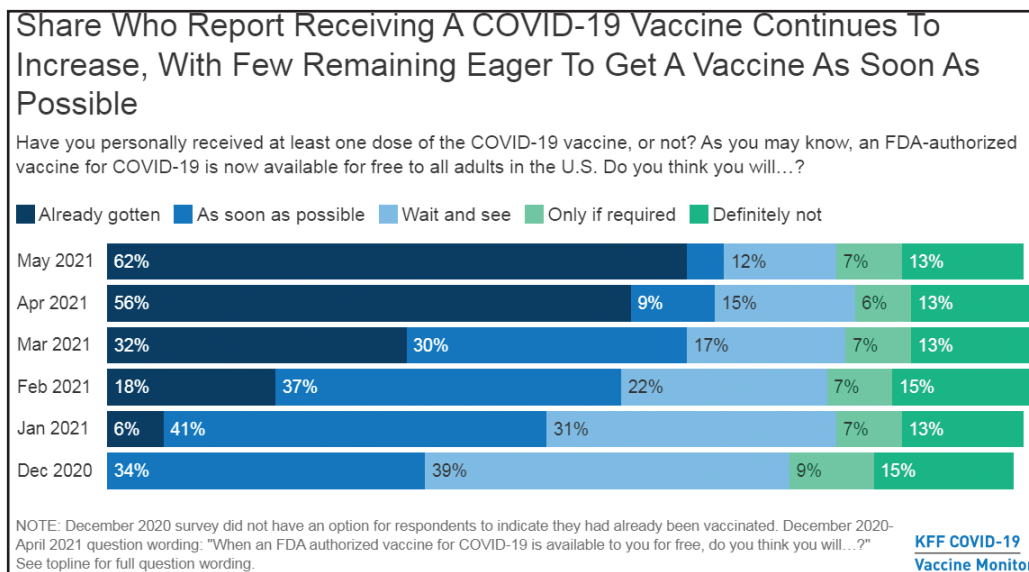
Over the three-month period, the percentages continued to decrease in all categories for Black, Latinx, and White respondents with the exception of a slight increase in the “System Distrusters” category for White Americans. However, African Americans still led the distrusters category. This group includes people who genuinely believe that people of their own race are not treated fairly by the health system.

Segment	Democrat		Independent		Republican	
	January	March	January	March	January	March
<b>COVID Skeptic</b>	6.0%	6.7%	16.4%	18.1%	32.6%	25.6%
<b>System Distruster</b>	11.3%	5.2%	15.6%	11.4%	13.9%	12.1%
<b>Cost-Anxious</b>	10.2%	6.3%	7.7%	10.8%	3.9%	7.6%
<b>Watchful</b>	15.7%	5.1%	15.0%	6.2%	12.6%	6.5%
<b>Enthusiast</b>	51.4%	28.3%	42.1%	19.0%	32.2%	14.4%
<b>Vaccinated</b>	2.0%	48.5%	0.5%	33.9%	0.1%	33.7%



## Who Are the Vaccinated?

Fourteen months into the COVID-19 pandemic (roughly the middle of 2021), 62% of U.S. adults had received at least their first COVID-19 vaccine, leaving a substantial portion of the adult population in the “vaccine hesitant” category -- those who had not received a vaccine yet, and those who had no plans of getting vaccinated. A report from the nonprofit Kaiser Family Foundation found that many of the adults who had not yet received the vaccine were still interested in doing so, which was encouraging data. Their views of getting vaccinated, along with their views of the pandemic more broadly, appear below.



By May 2021 (14 months into the pandemic), a majority of U.S. adults had received a COVID-19 vaccine, with 62% of adults receiving at least the first shot. People who have been vaccinated or who were “previously infected by COVID-19 have lower rates of severe illness and death than their unvaccinated peers.”

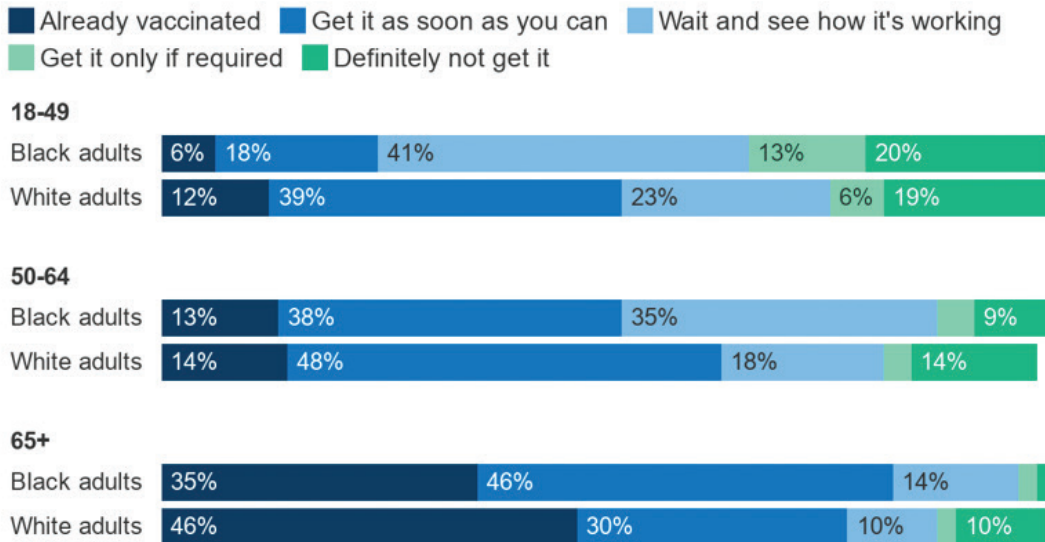
White Americans, who were vaccinated at a higher rate than Black and Latinx people, made up a larger share of those who had been vaccinated, but that gap shrank over the next six months. A study published on January 24, 2022, in the Journal of American Medicine found that vaccine hesitancy had decreased more rapidly among Black people over the previous 12 months. The report suggested that African Americans who were initially hesitant about getting vaccinated had gained more trust in the vaccines, the delivery methods, and/or in health care professionals. According to Tasleem Padamsee, an assistant professor at Ohio State University, “Black Americans were more likely over this period to develop the belief that COVID vaccines were necessary to protect themselves and their communities, and we know that belief is associated with a willingness to use the vaccine.”

## Who Are the Unvaccinated?

It is encouraging news that nearly 80% of both Black and White senior citizens said that they are most willing to be vaccinated, including those willing to get a vaccination even if it is not mandatory.<sup>10</sup>

## Large Majorities Of Both Black And White Seniors Are Eager To Get Vaccinated; Gaps Emerge At Younger Ages

Have you personally received at least one dose of the COVID-19 vaccine, or not? When an FDA authorized vaccine for COVID-19 is available to you for free, do you think you will...?



NOTE: See topline for full question wording.

SOURCE: KFF COVID-19 Vaccine Monitor (Feb. 15-Feb. 23, 2021)

**KFF COVID-19**  
Vaccine Monitor

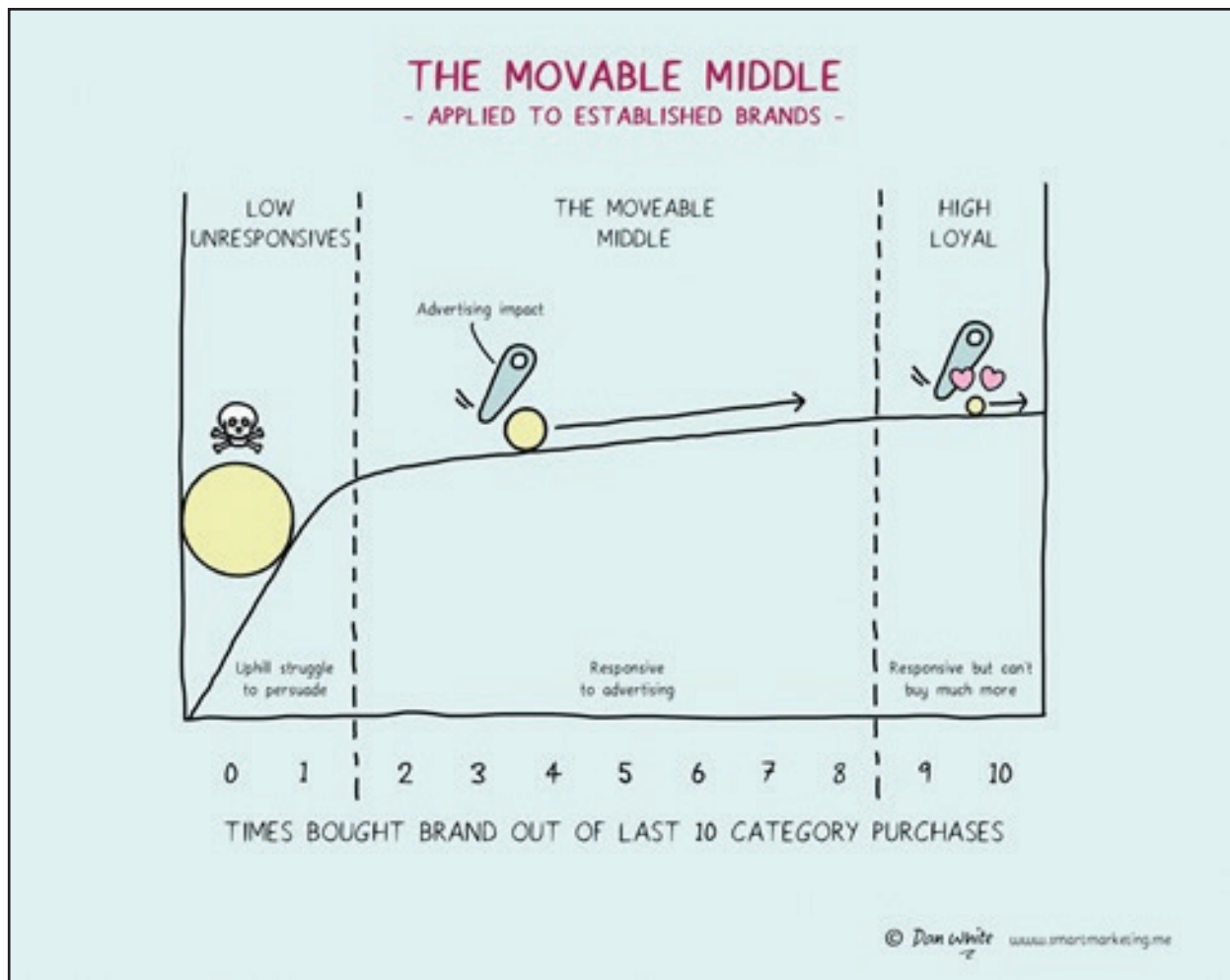
Calculating exactly “how many” and “who” is not vaccinated is more complicated, since it is easy to take a headcount of the people who have shown up and received their shots. However, “counting” exactly who has not shown up for their shots can only be estimated.

Unsurprisingly, most unvaccinated parents say they will “definitely not” get their 12-17 year-old or their 5-11 year-old vaccinated for COVID-19, according to the Kaiser Family Foundation.

### **What is the Moveable Middle?**

One market research approach examines who might buy a particular product or service by dividing potential customers into three groups:

- **“Low responsives”** to the sales message and/or the product, where it will be an uphill battle to persuade them to buy it.
- **“High loyal”** are the loyal customers who are already invested in the product or service at such high rates that they are unlikely to buy much more.
- **“The movable middle”** is composed of individuals in the middle of the marketplace who have not rejected the product or service, and who are not in the “high loyal” group either. However, they might be willing to move into the “high loyal” group with a little persuasive coaxing (advertisements or marketing with a different message, messenger, or price that is more compatible with the customer’s budget).



Similarly, COVID-19 vaccination research continues to suggest that there are individuals who are firmly opposed to ever receiving the vaccines (low responsiveness), and there are those who have already received one or more the vaccines and booster shots (high loyal). However, there is a significant number of people who are open to being swayed in favor of getting their vaccines and boosters. Collectively, we all have a vested interest in persuading this “malleable middle” to move into the ranks of the fully vaccinated. Recognizing that as much as 20% of the adult population has taken an unwavering position *against* being fully vaccinated, we will never reach herd immunity until large numbers from the malleable middle have moved into one of the “vaccinated” categories.

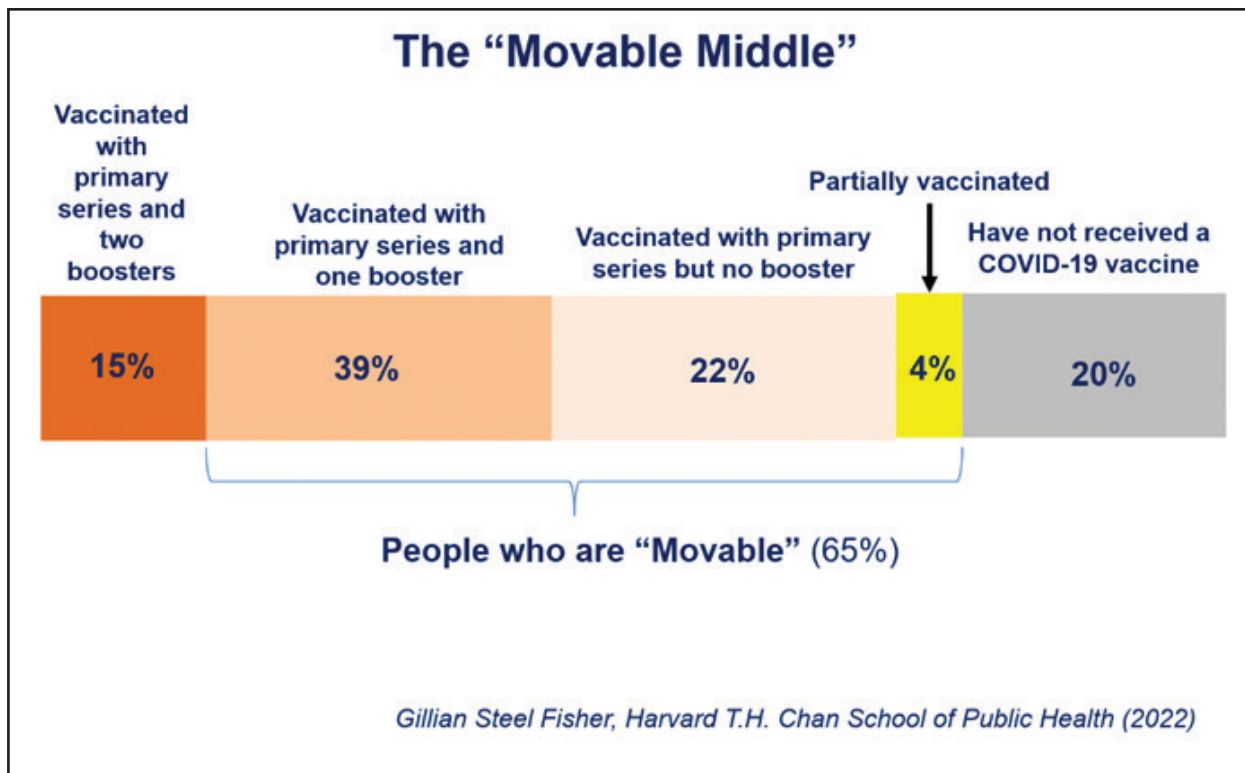
The development of safe and effective COVID-19 vaccines is a great step forward in our global effort to end the pandemic, which should be exciting news to everyone, but there are still some people who are skeptical or who hesitate when it comes to taking the final steps in vaccination. Chances are, you know a person who falls into this category.

The Surgo Ventures research recommends that we tap into the special needs and interests of each group to bring us closer to the 100% participation mark. The researchers suggest that the greatest return on our time invested will come from efforts directed towards three groups (1) the “Watchful,” (2) the “Cost-Anxious,” and (3) the “System Distrusters.” They constitute the “movable middle” that requires an attractive message tailored to appeal to their interests that will move them from vaccine hesitancy to fully vaccinated.

- **Enthusiasts**
  - make it easy for them to get the vaccine.
  - make it visible that they have been vaccinated.

- **Watchful**
  - Make it visible that others have been vaccinated or have positive intentions to do so.
  - Have their health providers appease their concerns about possible side-effects.
  - Allow for uncertainty through a “vaccinate later” option with a timeline or commitment attached.
  
- **Cost-anxious**
  - Prioritize communication from credible messengers that vaccination is totally free.
  - Bring the vaccines to the people.
  - Offer employees paid time off to get the vaccine.
  - Make any payments small and the process to pay easy.
  
- **System Distrusters**
  - Listen and learn from community concerns.
  - Partner with trusted community leaders, community organizations (Black churches), healthcare providers, etc., and ensure convenient and familiar location choices for vaccines.
  - Make it visible (billboards, electronic screens, or posters) that increasing numbers of people in the community are getting vaccinated.
  - Track and illuminate efforts for ensuring that there is equity in vaccine distribution and safety.
  
- **The COVID Skeptics**
  - Enlist the support of credible and familiar people who are trusted by this group as “local community vaccine ambassadors.”
  - Continue exploring and brainstorming new ideas for reaching this group and changing their minds.
  - Prevent misinformation from taking wider hold in the community by keeping them informed with accurate information like this handbook..

Dr. Gillian Steele Fisher from Harvard’s T.H. Chan School of Public Health offers the following graphic that defines who constitutes the “movable middle” in COVID-19 vaccinations. According to Dr. Steele Fisher, on the far left are those who have been fully vaccinated along with receiving their two booster shots. They constitute 15% of the population. Approximately 39% of the population has received their initial COVID-19 shots along with one booster shot, while 22% of the population has taken only the primary series vaccinations, but no boosters. Around 4% of the population is considered only partially vaccinated, leaving 20% of the people who have not received their COVID vaccine, nor a booster shot, and don’t intend to do so at any time in the foreseeable future. Individuals on the far ends of the continuum will firmly remain in their positions, while 65% of those in the movable middle can be pushed into the “fully vaccinated with boosters” category with the proper coaxing (more information, easier access to vaccines or information, etc.) to prompt that movement.

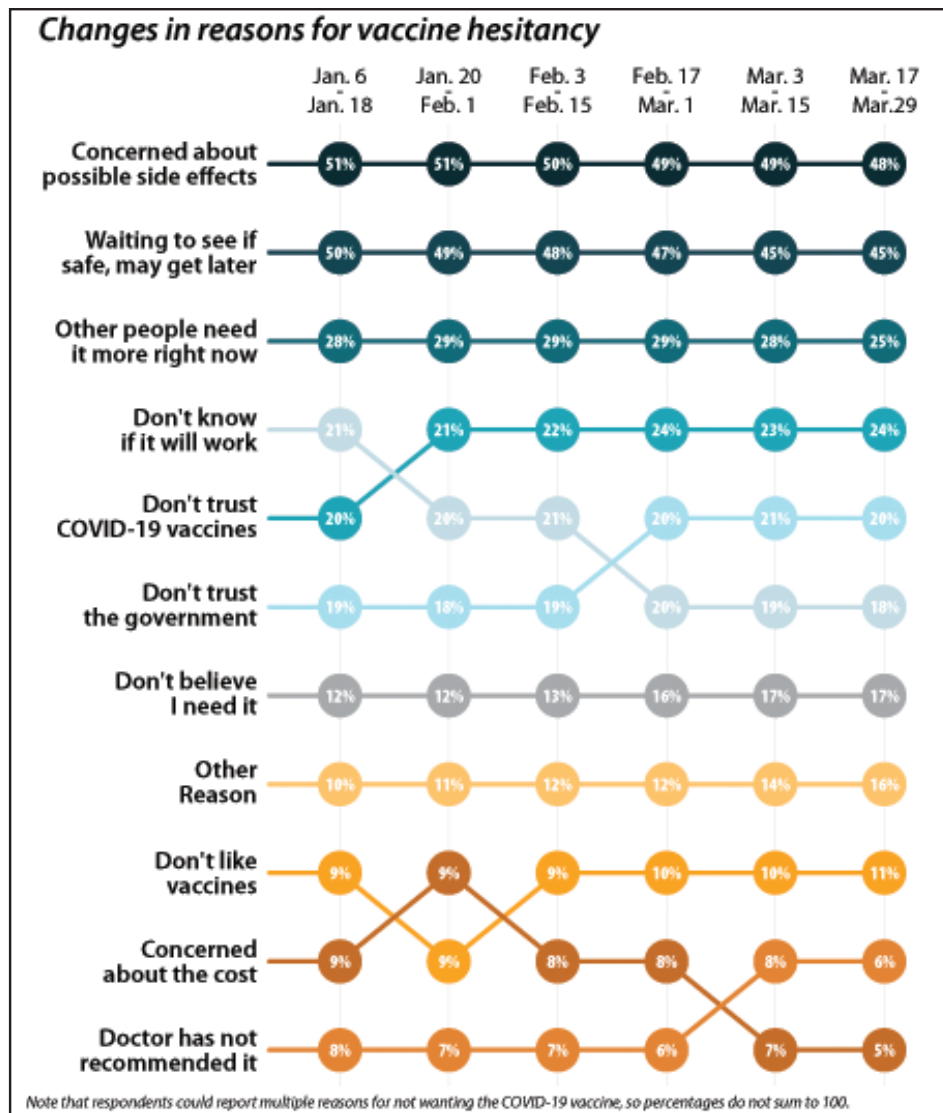


**What are the reasons for the delay in getting vaccinated?**

If we were to craft a story about “America’s Most Unvaccinated,” it would tell a tale with a broad mix of overlapping and sometimes contradicting fears and suspicions, some wild and some believable conspiracy theories, concerns about the safety of one’s family and community, and generalized skepticism of powerful institutions -- primarily the government and drug companies.

One approach by public health experts has been the simple catch phrase: “If we build it, they will come.” Although COVID-19 vaccines are readily available (already built), still millions of Americans opt out with no plans of ever coming forward to roll up their sleeves for the vaccine. Some vaccine strategists say that the approach should be more on the order of, “We are making the vaccine. It will be released when it is safe. We’ll bring it to you the moment we are certain that we know it is 100% safe and effective.” This audience is composed of the people who are most vulnerable to serious illness from COVID and the highly contagious Delta variant. They are also most likely to carry the virus, spreading it further.

Some of the most frequently cited reasons for vaccine hesitancy are captured in the chart below, titled, “Changes in reasons for vaccine hesitancy.” While all of the listed reasons for vaccine hesitancy remained the same over time, the number of people subscribing to them continue to shift with time.

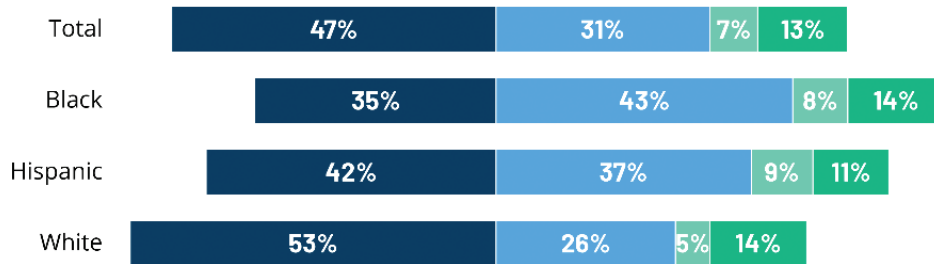


In a January 2021 survey of Americans, more than 4 in 10 Black adults said they would be hesitant about getting an FDA-approved vaccine when it is available. They would “wait and see” how a vaccine worked for other people according to researchers. As the number of people vaccinated increases, there is corresponding increase in the number of public places that can safely remain open indefinitely, without social distancing or protection masks.

## Black, Hispanic Adults Most Likely To Want To “Wait And See” Before Getting a COVID-19 Vaccine

Percent who say they will get a COVID-19 vaccine:

● Already gotten/As soon as possible ● Wait and see ● Only if required ● Definitely not



The reasons that millions of Americans still have not been vaccinated varies widely. There is a broad range of reasons that cause people, particularly those from marginalized groups, to hesitate in getting vaccinated. Some of the reasons have to do with not quite “understanding the numbers” -- the statistics relevant to COVID-19 .

- In “wading through all of the math,” many people:
  - overestimate the degree of risk involved in getting a vaccine.
  - underestimate their risk of succumbing to COVID-19 without a vaccination.
  - underestimate the serious (and life-threatening) consequences from contracting COVID-19.
  - hear the statistics, but do not understand how to interpret statistical information.
  - do not understanding risk rates (e.g., “1 in 1 million chances of an adverse health outcome.”) It is helpful to give them numbers with a familiar context like, “One person in our entire county.”

The reasons for remaining unvaccinated include the following groups and their subcategories:

**1. Access:** Everyone who is six months of age or older is eligible to receive the primary COVID-19 vaccine series as well as a bivalent booster dose.

- **Appointment availability:** Some people have encountered obstacles to obtaining shots (available times, locations, “appointment-availability” obstacles, as well as COVID-19 websites that are frequently crashing). In some cases, the distance required to travel to a vaccination site was excessive particularly in rural areas. For low-income individuals, transportation was frequently cited as an obstacle (no vaccine clinics nearby or the distance required to travel to a vaccination site) although they were enthusiastic about getting vaccinated.

Black and Latinx people in the United States are less likely than their white counterparts to have Internet access reliable enough to make online appointments, to have work schedules flexible enough to take any available opening, or to have access to dependable transportation to and from vaccination sites.

A lack of access to up-to-date information about the vaccine through trusted providers can also lead to uncertainty and give the appearances of an unwillingness to get a shot.

The California Department of Public Health has worked diligently to ensure that COVID-19 vaccines are available to all people in an equitable manner. Neighborhood vaccine clinics, in-language resources, and Community Conversations have helped to clear these obstacles.

- **Cultural barriers:**
  - The available information may not be not printed in the individual's language.
  - Some Latinx farmworkers reported that they were turned away from community-based COVID vaccination centers for various reasons.
- **Cost:**
  - It can take effort and resources to get high quality healthcare, which White and/or wealthy Americans are more likely to have. African Americans are less likely than their White American counterparts to have private health insurance.
  - There are health insurance barriers. Whether an individual has health insurance or not, can determine any rare out-of-pocket costs.
  - Individuals who have delayed their own medical care over the course of the past year or more are afraid of incurring medical costs for both COVID and other medical issues that may be discovered.

## 2. Confidence:

- There is a common mistrust of large healthcare systems.
- There is often a lack of cultural diversity and competence among physicians.
- Some “in the middle” are waiting to get a COVID shot from someone they trust (typically their primary care physician or a doctor they have seen in the past).
- There is an idea that COVID-19 is no worse than the flu (so, if you are healthy, then you don't need a vaccine.)
- There is a long-standing and historical mistrust of the government due to a history of past mistreatment of marginalized people (an example of the cited evidence: There is a disproportionately high number of environmental hazards found in and around minoritized neighborhoods and low-income communities).

The primary benefit of any vaccine is that it has been tested and is safe. The medical experts describe COVID-19 vaccines as “optimally tailored to generate an effective immune response.”

## 3. Convenience:

- “I will wait for the time when getting my COVID vaccine is most suitable to my work and personal schedules.” Nationwide, about 97% of people hospitalized with COVID-19 are unvaccinated according to federal data. Hospitalization is far more *inconvenient* than vaccination and will certainly take up more time impacting one's schedule.
- Needed childcare in order to get vaccinated.

## 4. Complacency:

- “I do not believe COVID is actually dangerous.”
- “COVID is a hoax and presents no clear or immediate danger to me.”
- Some have skipped vaccinations up until now, but said they might be persuaded at their next checkup, to get a vaccination based on advice from their own doctor.

## **What is the impact of Misinformation, Disinformation, and No Information?**

Part of vaccine hesitancy involves not merely a lack of reliable information, but it also requires unraveling (a) misinformation, (b) incomplete information, (c) disinformation (deliberate distortions and intentional health falsehoods) about vaccines and (d) misinterpretations of commonly accepted facts. The unvaccinated spend a considerable amount of their time on social media sites (WhatsApp,



Facebook, YouTube, Twitter, TikTok, Instagram, etc.) which serve as their primary source of negative and unreliable information.

According to researchers, misinformation has a higher appeal to those who are already anxious and afraid. One study found that negative videos about vaccines outnumbered positive videos by 3 to 1, with the negative videos getting for more viewing time once opened. Research has found that social media helps reinforce the following sentiments:

- “If I wait and get infected naturally, it will lead to a stronger immunity.” The truth is that there is no guarantee that you will survive COVID-19, particularly if you are unvaccinated. A study published by the National Library of Medicine reported that if you had COVID-19 previously and do not get vaccinated, your risk of getting reinfected is more than twice as high as those who are infected but have been vaccinated.<sup>11</sup>
- “This is about my civil rights.” The U.S. Constitution makes no mention of vaccinations. The rights of others to their “life, liberty, and the pursuit of happiness” is jeopardized by the choices of the unvaccinated. In most places, coronavirus vaccinations are only “recommended.” While we enjoy constitutional freedoms in America, including the freedom of speech, we should not feel free to harm or endanger the lives of others.
- “Getting vaccinated only involves my personal choice and my personal rights.” No one has a personal right to infect others, put them at the risk of infection, or to endanger them with hospitalization or death. What choice are the unvaccinated leaving others? A December 2021 KFF Vaccine Monitor reported that over 51% of Americans see vaccination as a personal choice, while only 47% believe it is a part of our responsibility to protect the health of others. Many of the most recent outbreaks of measles, mumps, rubella, and pertussis have been linked to largely under-vaccinated communities.
- In the initial Surgo Ventures study, 41.9% of respondents believed at least one COVID-related conspiracy theory (“tracking chips have been placed in the vaccine,” “vaccines can be used to control people,” “vaccines are part of a government plot,” “vaccines were designed to influence global events,” etc.) The second survey in March indicated that this figure had not budged, but had slightly increased to 42.1%. Conspiracy theories have been largely fed across social media platforms on the Internet.

To the surprise of medical experts, in March 2020, Elon Musk, the founder of Tesla, weighed in on the topic and predicted that the U.S. was likely to have “close to zero new cases” of COVID by the end of April 2020. Unfortunately, a considerable percentage of the COVID-19 misinformation came from the White House during the first 18 months of the pandemic.

At that time, the occupant of the White House had a habit of forwarding misinformation on Twitter as well as making questionable and false COVID-related statements at news conferences, further feeding into the distrust of government, medicine, and our political leaders. In July 2020, the president tweeted that “Everyone is lying. The CDC, media, Democrats, and our doctors.” His sharing messages (without a shred of evidence), that the CDC, and its doctors were “lying,” encouraged more vaccine skepticism and hesitancy. Trump supporters consistently referred to the pandemic as “a hoax” and quoted him as the “trustworthy” source of that false claim undermining our national public health.<sup>12</sup>

Cornell University analyzed 38 million English-language articles about the COVID-19 pandemic and determined that President Trump was the #1 source of COVID-19 misinformation. Regrettably, there is a low level of trust between the people and their politicians internationally, and our president’s remarks and behavior contributed substantially to that sentiment.

As unfounded claims that COVID-19 was a “man-made virus” circulated on social media, Dr. Anthony Fauci, who at the time was the head of the National Institute of Allergy and Infectious Diseases (1984-2022), became the primary political target of right-wing resistance to the COVID-19 health and safety protocols. The CDC was regarded as the world’s *best* public health body until its reputation was tarnished by relentless partisan assaults. In June 2020, Dr. Fauci said “There is a general anti-science, anti-authority, and anti-vaccine feeling among some people in this country—an alarmingly large percentage of people, relatively speaking.”

Unlike other times in world history, there is an unprecedented speed at which misinformation can spread today via the Internet which increasingly puts more lives at risk. The World Health Organization warned of both a pandemic and an “info-demic” -- a crisis caused by incorrect public health information being spread by numerous online sources. One researcher found that 73% of the COVID-19 misinformation and medical conspiracy theories on Facebook originated from just 12 individual sources on the social media platform. Those “information suppliers” exploited old fears and generated more understandable mistrust.

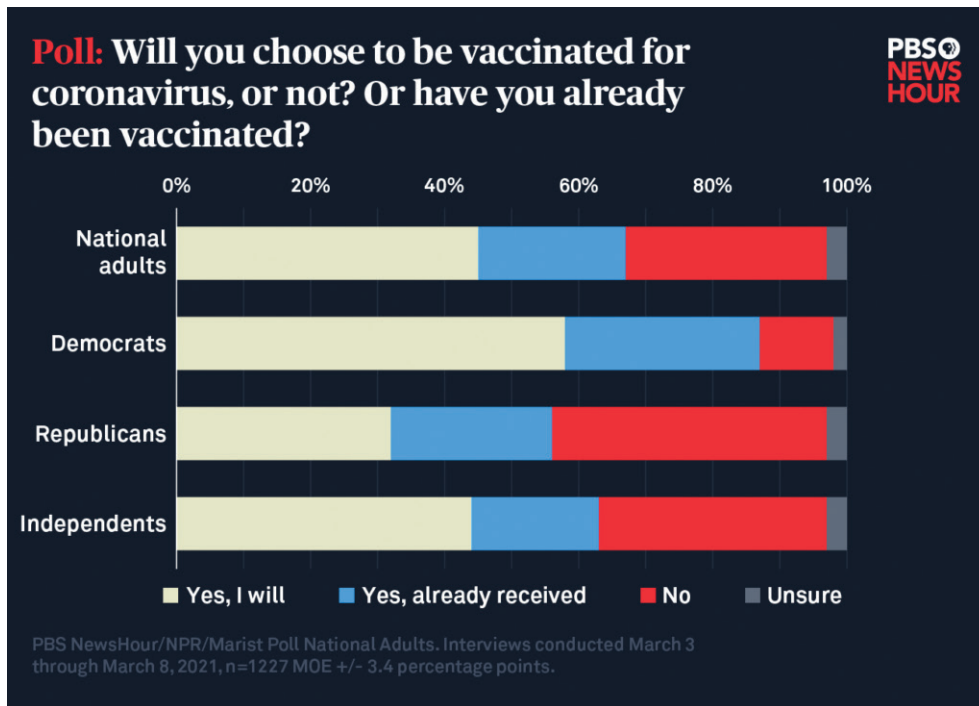
One widely recognized, unreliable source of Internet misinformation was Robert Kennedy, Jr., son of the late US Atty. Gen. and 1976 US presidential candidate, Robert F. Kennedy. Social media companies have removed some of his content and are trying to clamp down on COVID-related medical misinformation. Kennedy was banned from Instagram, but remains on Facebook, with more than 300,000 followers, and on Twitter, with over 225,000 followers who share his misleading content with others. Fear mongering and casting doubt on the knowledge of health experts served to downplay the significance of lifesaving vaccinations, which has resulted in an unspecified number of hospitalizations and deaths. The role of the Internet should not be underestimated in its ability to promote vaccine hesitancy.

The misinformation, disinformation, mixed messages, and anxiety collectively contribute to vaccine hesitancy or “decision paralysis” (also known as “paralysis by analysis”). “Waiting to see” turns out to be one of the most dangerous strategies.

Perhaps your best source for truthful information about COVID-19 vaccines will come from your medical doctor’s office or a publication from a responsible source (not an Internet blog, Facebook, Instagram, or twitter). There are numerous medical and professional organizations, including but not limited to the American Medical Association and the World Health Organization, which provide reliable and verifiable information related to COVID-19 and the currently available vaccines.

### **Do Politics Influence Vaccine Hesitancy?**

Vaccine acceptance rates differ noticeably along partisan (political) lines. A closer look at political parties reveals that most Democrats (90%), Independents (74%), and Republicans (69%) have already received their vaccinations for COVID-19. However, 29% of Republicans, and 19% of Independents report that they have no intentions of getting a COVID-19 vaccine regardless of its availability. Statistics indicate that those who are better educated, earning higher incomes, and leaning Democratic politically, (as well as senior citizens) are most likely to have received their COVID-19 primary series and booster shots.<sup>13</sup>



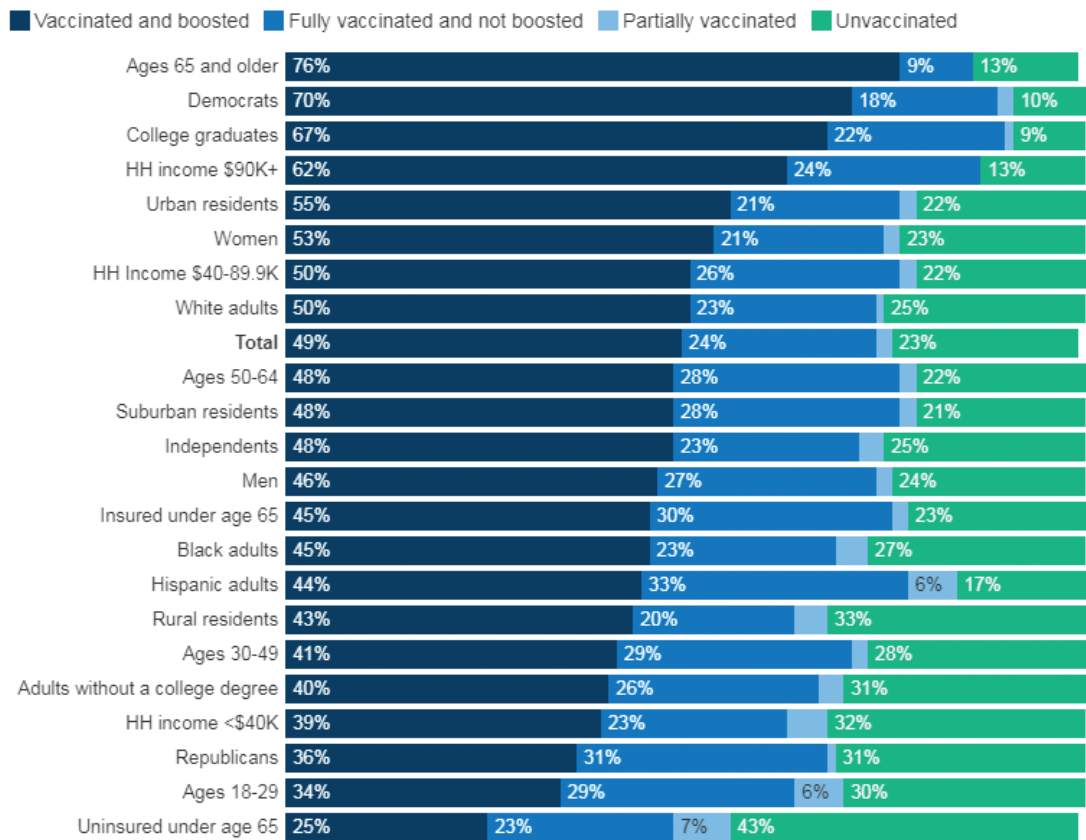
A 2021 survey by Surgo Ventures found the following vaccine behavior plans distributed by political affiliation:

Timing	Democrat	Republican	Independent
Vaccinated	48.5%	33.9%	33.7%
Get the vaccine as soon as it's available	24.5%	15.3%	11.2%
Wait three months before getting it	7.4%	8.2%	8.2%
Wait a year before getting it	5.4%	9.8%	8.5%
Don't know	8.3%	9.3%	11.6%
I would not get the vaccine	5.9%	23.5%	26.5%

One survey concluded that those firmly opposed to ever getting a vaccine outnumbered those willing to be swayed. Unless we find an effective strategy to persuade the unwavering 17-20% (in the “definitely no” category), achieving herd immunity and escaping the coronavirus pandemic completely could be a long way off.

## College Educated Adults, Democrats, Those With Higher Incomes, And Seniors Remain Most Likely To be Vaccinated And Have Received Their COVID-19 Booster Dose

Have you personally received at least one dose of a COVID-19 vaccine, or not? If yes, are you partially vaccinated, meaning you received just one dose of a two-dose vaccine, are you fully vaccinated but have not received a booster, or are you fully vaccinated and have also received at least one booster shot?



NOTE: See topline for full question wording.  
SOURCE: KFF COVID-19 Vaccine Monitor (July 7-17, 2022) • PNG

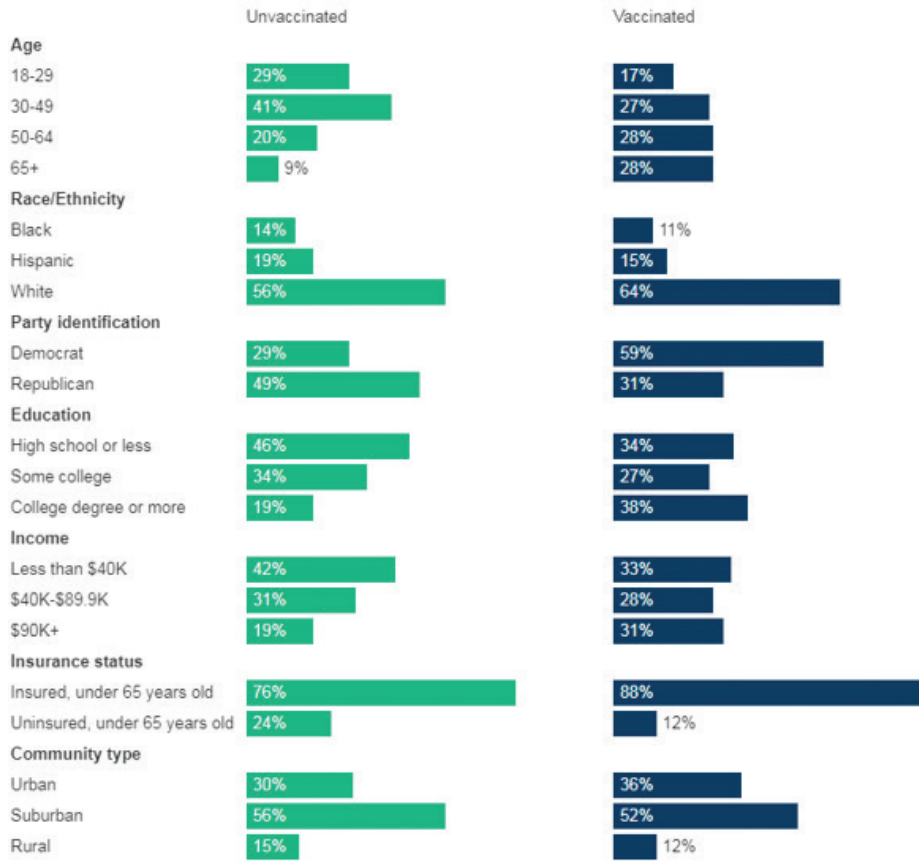
KFF COVID-19  
Vaccine Monitor

Nearly 80% of adults in the U.S. are now vaccinated to some degree for COVID-19. However, 19% of all adults and 81% of *unvaccinated* adults say they will “definitely not” get the COVID-19 vaccine now or at any time in the future. Only 4% are open to getting vaccinated at some future point, according to one report.

The Kaiser Family Foundation COVID-19 Vaccine Monitor provided a chart depicting the profile of the unvaccinated below.

## Compared To Those Who Have Received A COVID-19 Vaccine, Unvaccinated Adults Are Younger, Less Educated, More Likely To Be Republicans, People Of Color, And Uninsured

Demographic profiles of vaccinated and unvaccinated adults:



NOTE: Vaccinated adults have received at least one dose of a COVID-19 vaccine. Party identification includes independents who lean towards either party. See topline for full question wording.  
 SOURCE: KFF COVID-19 Vaccine Monitor (May 18-25, 2021) • [Download PNG](#)

[KFF COVID-19 Vaccine Monitor](#)

The people who say that they will *never* get a COVID-19 vaccine are disproportionately likely to be White, evangelical, politically conservative, and to live in rural areas. They are overrepresented in the South and the Midwest. A high percentage of incarcerated men also fall into the “never will I be vaccinated, and I am not open to persuasion” category.

Several studies have suggested that Republican Party affiliation is one of the more reliable factors predicting who will fall into the group rejecting all vaccines. Those who say they are open to getting a shot, but are still in the “wait and see” mode are a broad collection of people, who tend to be a more diverse and urban group, including many younger people, Black and Latinx Americans, and Democrats.

## Who is most at risk of contracting COVID-19?

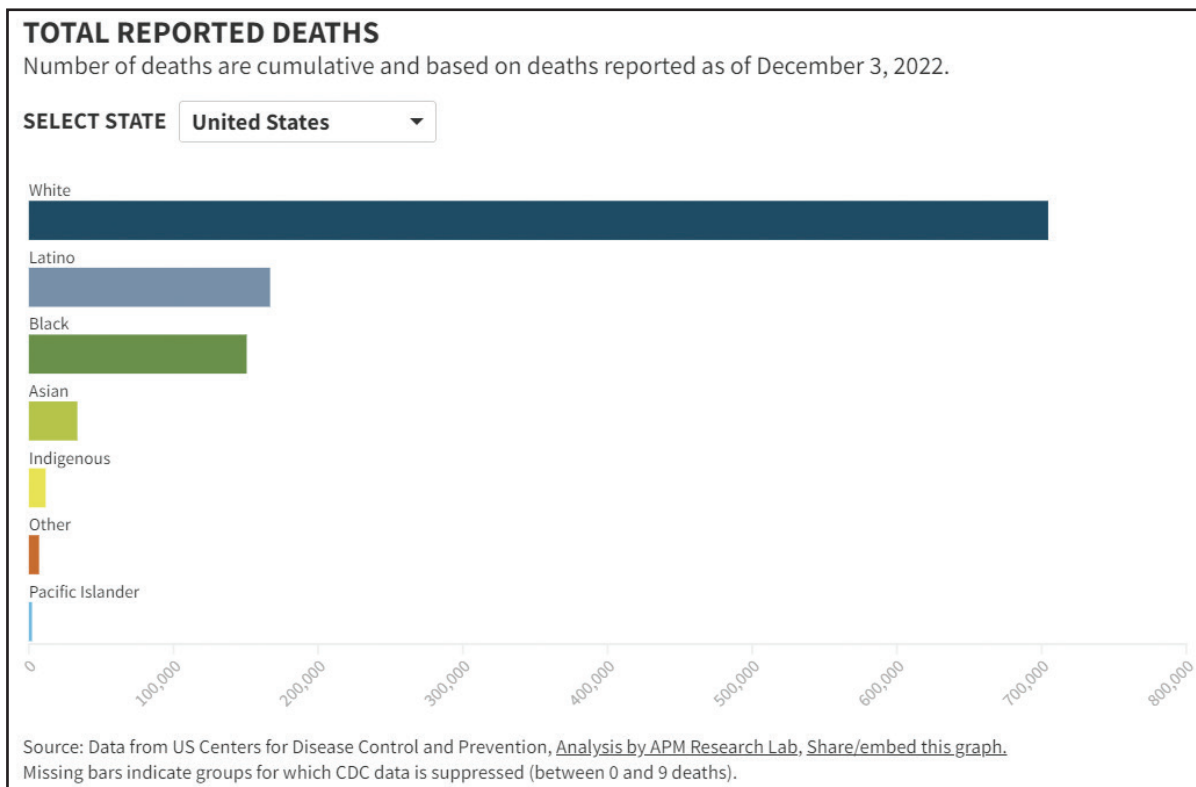
Although the distribution disparities are shrinking, communities with larger populations of Black and Latinx Americans have received a disproportionately smaller share of the available COVID-19 vaccines, making it potentially more likely that people of color will fall victim to the coronavirus. This may partially explain why the vaccination rate of African Americans is half that of White Americans. The gap for the Latinx communities is slightly larger according to the CDC reports on race and ethnicity.

In dissecting the data on mortality rates for each ethnic group based on their percentage of the national population, we find the following:

- Indigenous Americans suffer the highest rates of loss,
- second are Pacific Islanders, and
- African Americans are the third highest by percentage of the population.

Of the approximately 1,076,528 official COVID-19 deaths in the U.S., the number of lives lost by each ethnic group is as follows:

- Asian Americans = 33,600
- Black Americans = 150,593
- Indigenous = 11,664
- Latinx = 166,790
- Pacific Islander = 2,230
- White Americans = 704,529
- “Other” race = 7,122



During the first several weeks of the nation’s vaccination effort, hospitals and vaccination centers could not administer shots quickly enough for the millions of people who rushed to vaccination centers to receive the shots. Each state created its own priority list for vaccinations. The essential workers list heavily informed the vaccination prioritization schedules and included the following:

- First responders (medical personnel, police, firefighters)
- essential workers (teachers, health care workers, social workers)
- elderly patients who were at a higher risk of dying from COVID-19
- nonelderly people with pre-existing underlying health complications or severe disabilities.

The risk of serious illness from COVID-19 was very low among healthy children and adolescents, so they did not fall into the high-risk categories for severe COVID-19, and there was no urgency to vaccinate them ahead of the first responders and individuals with underlying illnesses.

**Are there special reasons why people of color should get vaccinated to prevent the spread of COVID-19?**

Yes! The COVID-19 pandemic has highly impacted communities of color, who are also overrepresented in essential workers and front-line occupations where the daily risk of exposure to COVID-19 is considerably higher.<sup>14</sup>

***The CDC COVID-19 data on African Americans indicate that Black Americans:***

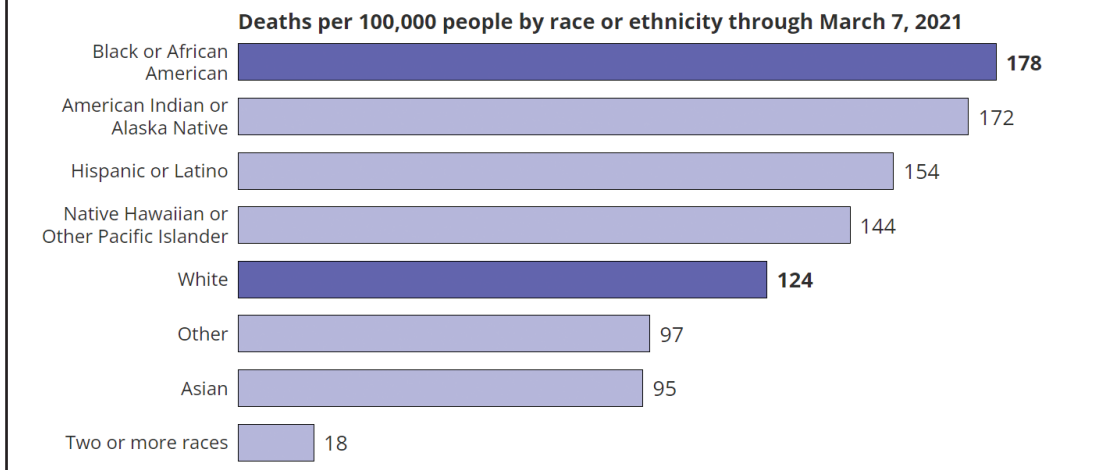
- are 2½ times more likely to contract COVID-19.
- are five times as likely to be hospitalized with COVID-19.
- are twice as likely to die from COVID-19.
- make up 12.6% of the U.S. population, but account for more than 14% of the COVID-19 deaths in the U.S. Many of their deaths were preventable, since vaccinations would have saved thousands of their lives.

Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity				
Updated Sept. 15, 2022 <a href="#">Print</a>				
Rate ratios compared to White, Non-Hispanic persons	American Indian or Alaska Native, Non-Hispanic persons	Asian, Non-Hispanic persons	Black or African American, Non-Hispanic persons	Hispanic or Latino persons
Cases <sup>1</sup>	1.6x	0.8x	1.1x	1.5x
Hospitalization <sup>2</sup>	2.7x	0.8x	2.3x	2.0x
Death <sup>3, 4</sup>	2.1x	0.8x	1.7x	1.8x

Race and ethnicity are risk markers for other underlying conditions that affect health, including socioeconomic status, access to health care, and exposure to the virus related to occupation, e.g., frontline, essential, and critical infrastructure workers.

Without vaccinations, other members of the African Americans community will remain vulnerable to catching COVID-19. Local, state, and federal government agencies must organize concerted outreach efforts to meet the unique concerns that impact people of color.

## Nationwide, Black people have died at 1.4 times the rate of white people.



### ***Is the COVID-19 here to stay?***

At the outset of the coronavirus pandemic, epidemiologists assumed that the rate at which COVID-19 would spread was comparable to the flu. And like the flu, they predicted that there would likely be only one outbreak per year and most likely in the fall. The actual spread of COVID-19 has not obediently followed their predictions.

Other experts forecasted waves of COVID-19 infections occurring 2-3 times a year. Unlike the flu, there turned out to be more *re-infections* with COVID-19. With the Omicron variant, prior COVID infections only provided about a 50% protection against reinfection. This makes nearly everyone vulnerable to multiple infections, which is why booster shots are not to be considered optional in our fight against COVID. The greater problem is that as COVID-19 mutates into new variants, its ability to re-infect those who have been previously infected with the virus actually increases because it is a different strain of the virus. As a result, a third or fourth COVID-19 infection is possible depending on the strength of one's immune system. However, booster shots can make a major difference determining who gets re-infected.

### **Parents, Children, and COVID-19 Vaccines**

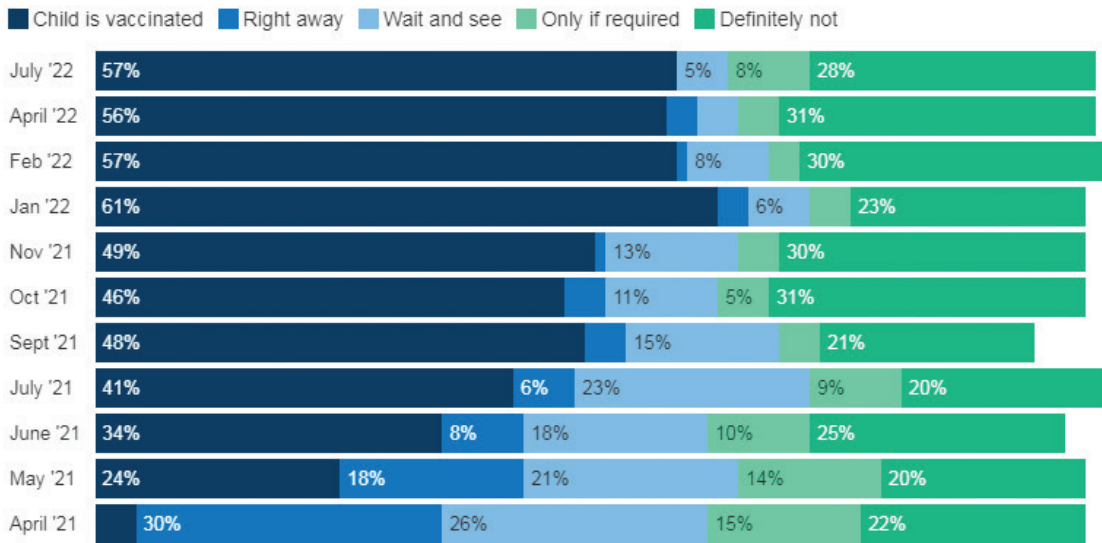
While early vaccinations among adults indicated that people of color were less likely to be vaccinated than White adults, the same pattern did not emerge with children. Among parents of teenagers, the percentage of parents who said their teens either are or will be vaccinated are as follows:

- 62% of Latinx parents
- 48% of Black parents
- 42% of White parents



## Vaccination Rates Among Children Ages 12-17 Have Plateaued Since The Start Of The Year

Thinking about your child between the ages of 12 and 17, have they received at least one dose of a COVID-19 vaccine, or not? If not, do you think you will get them vaccinated...?



NOTE: Among parents or guardians of children between the ages of 12 and 17. April 2021 question wording: "Once there is a COVID-19 vaccine authorized and available for your child's age group, do you think you will...?" See topline for full question wording.  
SOURCE: KFF COVID-19 Vaccine Monitor • PNG

KFF COVID-19  
Vaccine Monitor

Substantially more White American parents than either Black American or Latinx parents said that their teenager will “definitely not” get vaccinated. Parents wanted more information, and their concerns about the safety and potential side effects of the vaccine were evident when they identified the primary reasons why their child was not yet vaccinated or why they were leaning towards no vaccination at all for their child.<sup>15</sup>

### Safety Concerns

- 44% of parents said that their child becoming infected *from* the vaccine posed a greater risk than the virus itself (although independent studies have found the opposite to be the case.)
- 53% of parents of young children (ages 6 months through 4 years old) believed that being vaccinated is a bigger risk to their child’s health than getting infected with COVID-19 .
- 13% said they wanted to “wait and see” how the vaccine worked for other children before getting their child vaccinated.
- By a 3-to-1 margin parents saw protecting their children from getting sick as a bigger reason to get them vaccinated, rather than preventing their child from spreading COVID-19 to other family members or friends.

A substantial percentage of parents:

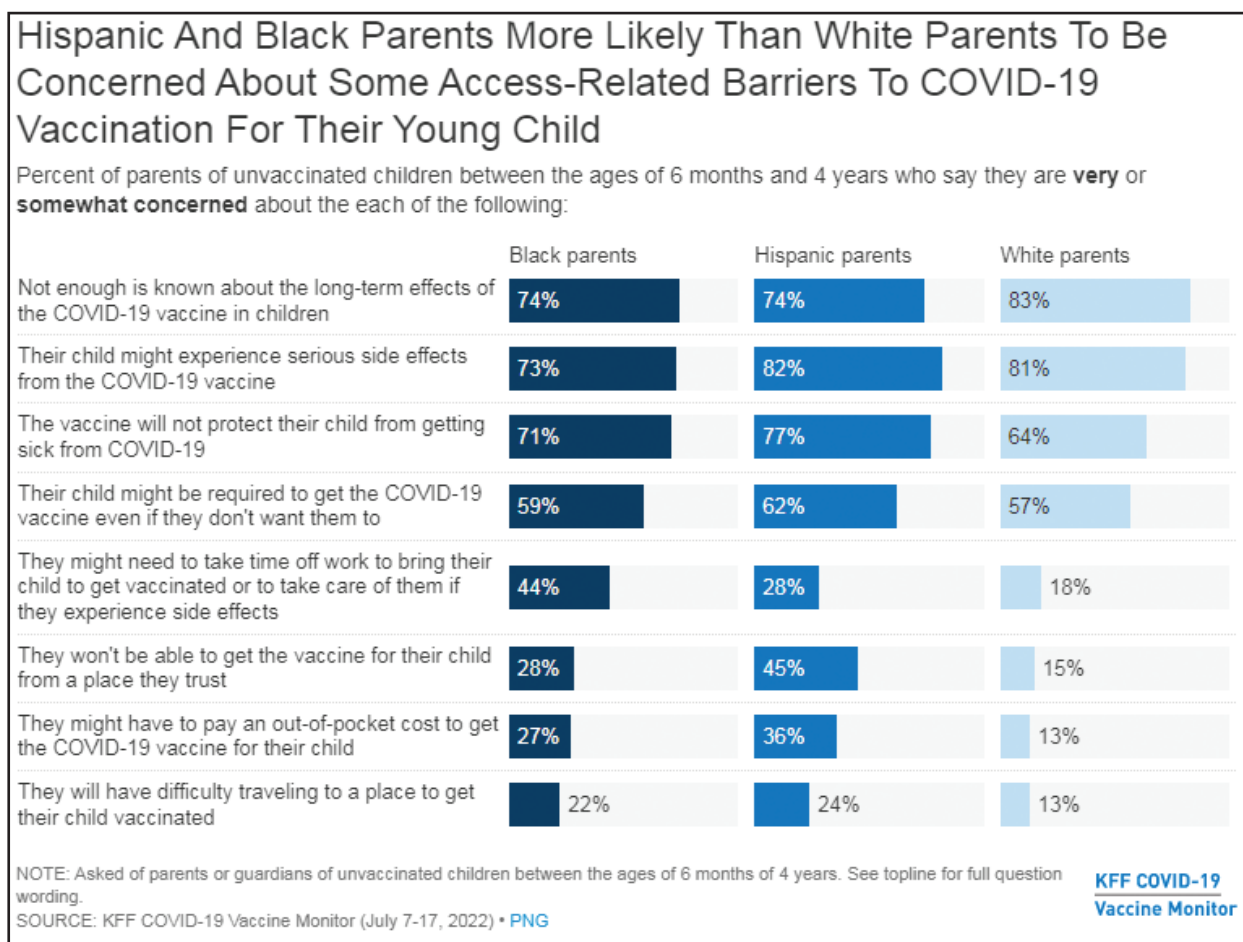
- felt there was not enough information on vaccines for children, which prevented them from getting their child vaccinated.
- had reservations about the potential side effects of their children.
- were not certain that the vaccine was “necessary” for children
- had children who did not want to get vaccinated”
- worried about the side effects. (However, the data so far suggest that the side effects in younger children are substantially milder than those in older adolescents or adults). Vaccinations for young children are prepared at such a

low dosage of the vaccine that there can be very few side effects, if any at all. Even parents who were vaccinated themselves said they were worried that their child would experience serious side effects from the COVID-19 vaccine.

- Approximately 28% of parents indicated that they should have the final say on whether or not their school-age child should be vaccinated, even if their unvaccinated child constituted a health risk for other children.

### Access Barriers

Access barriers are a common concern for some parents when it comes to getting their children vaccinated. Latinx parents, Black American parents, and those with lower incomes are more likely than other parents to say they are concerned they (1) might have to miss work to get their child vaccinated, (2) don't have a trusted place to go, or (3) that they will have difficulty traveling to a vaccination location.



- 31% of parents are concerned about needing to take time off work to get their child vaccinated.
- 22% are concerned about not having a trusted place to go for the vaccinations.
- 17%) are concerned about the difficulty in traveling to a designated site to get their child vaccinated.
- Black American and Latinx parents are more likely than White parents to say they are worried about each of these barriers to access.
- Parents with lower household incomes are more likely than those with higher incomes to express these concerns.

### **Information Needs**

- Parents want more information on vaccinations for children and teens.
- Younger parents, those without college degrees, Republicans, and unvaccinated parents, are prominent among those most likely to say they “don’t have enough information” to make a decision about vaccination for their child.
- Approximately 50% of parents of school-age children say their child’s school has provided information about how to get their child vaccinated for COVID-19.

## **Question #2:**

### **Why has vaccine hesitancy remained such a challenge to the African American community?**

Black Californians have one of the lowest life expectancies in California and they disproportionately face higher COVID-19 mortality rates. However, their vaccine hesitancy rates are putting thousands of Black American lives in peril.

Today, African American patients often receive differential treatment and experience a disparity in access to services compared to White patients with similar illnesses, complaints, or symptoms.

- One analysis showed that, from 2008 to 2017, Black American and Latinx heart failure patients admitted to hospitals were significantly more likely to be admitted to the general medical service than the specialty cardiology service. White Americans tended to be directed to cardiology specialists. (The insurance status of the patients did not explain the differences.)
- Death rates from breast cancer are 40% higher among Black American women compared to White women.
- Black American mothers die in childbirth at 3-4 times the rate of white mothers in the U.S.
- Nationally, Black Americans have worse outcomes for many types of cancer, including lung, colon, cervical, breast, and blood cancers, due in part to the fact that they are often misdiagnosed or only diagnosed at later stages of the illness.

The long-term medical and psychological consequences from these disparities in treatment due to race can be equally as frightening when illnesses go undetected or untreated for years or decades. Many hospitals have begun to involve patients in studying ways to improve patient care, now referred to as “participatory research,” which should reduce the hesitancy some African Americans experience, which keeps them from taking advantage of necessary medical services and treatment.

The disparities in patient treatment are nothing new. One 2016 survey found that up to 50% of White medical students and residents still believed in numerous false biological differences between Black and White patients. Twenty-five percent of them agreed with the claim that “Black Americans have thicker skin than White Americans.” They also believed that Black Americans and White Americans have different levels of pain tolerance. Consequently, Black Americans are frequently undertreated for pain relief compared to White American patients reporting the same level of pain being experienced.

Another study found that African Americans are less likely than their White counterparts to be prescribed opioids for serious pain by their doctors. Research has shown that patients of color receive less information, less empathy, and less attention from their physicians regarding their medical care than their White counterparts. Further, African American patients are less likely to receive medical services than White patients with similar complaints and symptoms, according to the book from the Institute of Medicine entitled, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.*”

The reasons for vaccine hesitancy differ from community to community and even within neighborhoods throughout the United States. Black Americans often have different experiences that have led to vaccine hesitancy than their immigrant neighbors who may also be Black but relocated here from different parts of the world. Many African Americans have not only faced overt discrimination in health services and medical treatment, but there has been a long history of medical neglect and abuse experienced by Americans of African descent and other people of color.

### **A Troubled History with the Medical Community**

When addressing medical treatment, African Americans have not merely been underserved medically, but often they were (1) mistreated, or (2) barred from receiving any medical treatment at all. Medical apartheid has been the most common medical experience for African Americans. One medical researcher stated that, “Among the Black American community, concerns about human testing make trust in government right now very tenuous,” when it comes to COVID-19 vaccines.

Institutional racism and historical inequities in healthcare play a significant role in vaccine hesitancy among African Americans and other people of color.<sup>16</sup> Verified incidents of medical practitioners endangering the health or betraying the trust of Black American patients have damaged the relationship between the medical community and Black Americans.

It has been said that race has been a “four-letter word” to American medicine, which has always had a problem with people of color. For decades, although their numbers were small, Black American physicians were prohibited from becoming members of the American Medical Association. In 2008, the AMA publicly apologized for its century-and-a-half-long record of mistreating African American physicians. The apology came on the heels of a *Journal of American Medicine* paper published by a panel of independent experts, which among other things, detailed how the AMA worked aggressively to close African American medical schools. Their efforts were intended not only to deny African Americans adequate medical treatment, but also to minimize the number of advocates standing up for proper African American health care.

The first official AMA rejection of Black American physicians came in 1868. Subsequently, Black American physicians founded the National Medical Society (NMS) for licensed Black American physicians.<sup>17</sup> The National Medical Association, the collective voice for today’s 30,000 African American physicians, was established in 1895 by Daniel Hale Williams, an African American surgeon. Williams is credited with performing the “first successful heart surgery” in 1893 at Chicago’s Provident Hospital, the first nonsegregated hospital in the United States. It was not until the passage of the 1960’s civil rights legislation that discriminatory professional practices like those of the AMA were prohibited in the U.S.<sup>18</sup>

The shortage of African American health care practitioners contributed to the Black American distrust, as well as the long history of substandard services and care afforded Black American patients. Black Americans had no say in the final decision of what procedure, treatment, or care they would receive from a doctor or hospital.

Over the course of three and one half centuries, the bodies of people of color were subjected to medical abuse and experimentation in America. According to an article published by the Cherokee Registry, smallpox-infested blankets were deliberately distributed to Native Americans in the 18th century.<sup>19</sup> The Native Americans were given “gifts” of food in “large quantities,” some “600 Rations.” “Out of our regard to them we gave them two Blankets and an (*sic*) Handkerchief out of the Small Pox (*sic*) Hospital. I hope it will have the desired effect.”<sup>20</sup> Indeed, it did. The uncomfortable historical relationship between the American medical community and people of color is grounded in a deep-rooted saga of unethical treatment that fostered long-term mistrust.

The events and incidents below are presented to aid the understanding of vaccine hesitancy. For their own protection, people of color have learned to shun the advice from the American medical community. These historical accounts are not intended to provide an exhaustive or complete list of

reasons for vaccine hesitancy, but they shed some light that can partially explain what has led to vaccine apprehension in the African American community.

- The abuse of Black bodies began on **slave ships**.<sup>21</sup> Because individual Black captives represented a substantially valuable commodity, most slave ships had doctors (or someone assuming that role) aboard each ship. The “doctor” would regularly evaluate the health condition of the “cargo” and determine what medical care was mandatory for African captives traveling across the “Middle Passage” (the Atlantic voyage from Africa to the “New World.”) Dehumanization, torture, and brutality were the norm from the slave ship to the auction block. Sick or dying Africans were unceremoniously tossed overboard. Most merchants were unmoved by taking this drastic measure since the cargo was insured and the merchants would be compensated for “lost or damaged cargo.”
- **During enslavement** in America, Black women were frequently responsible for the daily care of the sick. However, plantation overseers or owners made all final health decisions, since the body of an enslaved person was considered the property of his/her owner, and not the enslaved individual. In extreme medical cases, a local doctor might be summoned depending on the perceived value of the enslaved person, but some Blacks were callously left to die.

Although there are recorded incidents of kindness exhibited by “kind slave masters” (mainly accounts of compassionate enslavement presented in American literature or history textbooks), the institution of American slavery itself had an international reputation for its brutality, rendering the “kind slave master” description a contradiction of terms. It was not uncommon for slaveholders to use vomit-inducing medicines as a punishment or torture for uncooperative slaves who resisted cooperation in the “peculiar institution” as slavery was referred to in America. Administering these medicines to the enslaved was also used as a form of “entertainment.”

- **Yellow Fever** ravaged Philadelphia in 1793. As the epidemic swept through Philadelphia, John Lining, a South Carolina physician, was summoned to assist the city. Based on observations of an earlier Yellow Fever epidemic in Charleston, SC, Lining proposed a useful strategy for Philadelphia. He said, “There is something very singular in the constitution of the Negroes, which renders them not liable to this fever.” Blacks were recruited to assist and assured that they would not be infected with Yellow Fever. Moreover, they should feel a “sense of duty, and do all the good for the people” of Philadelphia. Lining’s false assumption led to the deaths of between 200-300 Blacks who helped.



- A vast network of hospitals, medical schools, doctors, researchers, and anthropologists subjected enslaved African Americans and Black freedmen to **gruesome medical experiments** in both the North and the South. Pseudoscientific experimentation on enslaved

patients was commonplace, and doctors throughout the American South carried out these experiments uninterrupted by authorities or morality for decades.

- When live bodies were not available for research or medical training, grave-robbing was the “go-to” scheme for providing bodies for medical experimentation. While the fresh bodies of executed White prisoners were transferred to medical schools for dissection and training, Black cemeteries were frequently raided for fresh corpses that could be used for autopsies, medical training, and scientific study.
- In an 1824 advertisement for the **Medical College** of South Carolina, the school boasted about the number of corpses it would make available to its students for medical research, “... subjects being obtained from among the colored population in sufficient number for every purpose, and proper dissection carried on without offending any individual in the community.” (Which community?) Clearly, they were not referring to the Black community whose relatives and loved ones had fallen victim to well-paid grave robbers.<sup>22</sup>
- During the renovation of a 150-year-old building in Augustine, Georgia in the summer of 1989, construction workers made an unsettling discovery in the building’s dirt basement. Although grave robbing was “illegal” in Georgia for much of the 19<sup>th</sup> and 20<sup>th</sup> centuries, they discovered over 10,000 **human bones, torsos, and skulls** buried in the basement of the stately brick Medical College of Georgia. Forensics quickly identified that the bones found were relics from the education and research conducted by “doctors-in-training.” They were from cadavers who had been taken from their graves. Many of the bones displayed the signs of dissection, while others were labeled as specimens.
- In the mid-19<sup>th</sup> century, Dr. James Marion Sims (considered **the “Father of American Gynecology”**) used enslaved women exclusively as his patients to test out new surgical techniques and gynecology. The Black women were forcefully bound to the surgical tables which allowed Sims to conduct his experiments without the use of anesthesia. Like many others, he operated under the fictitious belief that Black people did not experience pain in the same way that White people did (a notion that persists to this very day) because of “their biological inferiority.” Black pain tolerance was considered by some to far exceed the maximum pain tolerance threshold of White Americans.

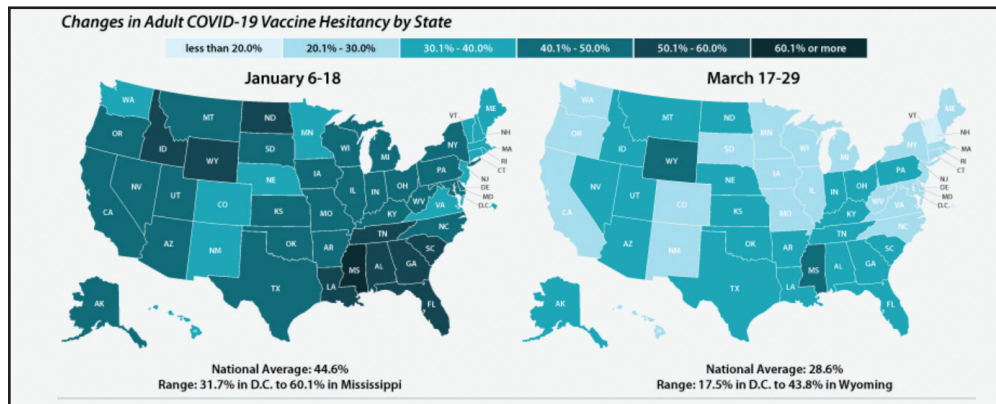
Most White Americans in the U.S. were thoroughly convinced of the notion of white supremacy, and American medicine was all too happy to reinforce this perception. The belief was used to justify slavery, and later, all other racist practices and ideas, no matter how illogical or contradictory the premise. “Deapetomania” was described as an uncontrollable desire of enslaved Blacks to run away, and it was considered a mental illness (by Whites only). Anthropologists even argued (in harmful “scientific” articles) that Blacks were biologically a different species than White Americans (although reproduction from interracial encounters would have been impossible.)

- In the 19<sup>th</sup>-century South, most **Caesarean sections** (“C-sections”) were performed on African American women, where the operation was “usually fatal for either mother or infant, and sometimes both,” according to Sharla Fett, a history professor at Occidental College in Los Angeles. It was commonly accepted that this procedure “...should not be done on White women because it was too risky.”
- In the early 20<sup>th</sup> century, Black women (as young as 11 & 12) were routinely given hysterectomies and **sterilized** without their knowledge and robbed of the opportunity to ever bear children. The highest number of these cases occurred in Mississippi). Among them was

the American Civil Rights icon, Fannie Lou Hamer, the cofounder of the Mississippi Freedom Democratic Party which bravely challenged the state's whites-only Democratic Party in 1964. "I would say about 6 out of the 10 Negro women that go to the hospital are sterilized," Hamer testified in 1964 as a member of a Civil Rights panel.

Although the Supreme Court in 1927 upheld a Virginia practice of sterilization on people considered mentally "unfit," Ms. Hamer concluded instead that, "It was a way to decimate the black population and keep it from increasing." Distrust of doctors persists to this day inside Mississippi's Black community. In a survey, more than 40% of Black Mississippians said they probably would not take the COVID-19 vaccine, or they are unsure whether they will take it, said Dr. Thomas Dobbs, Mississippi's chief health officer.

### *The "Why" Behind Black Vaccine Hesitancy (in Mississippi)*



### **The Infamous U.S. Public Health Service Study of Untreated Syphilis on Black Males in Tuskegee and Macon County, Alabama, 1932 -1972**

The United States has had a long history of medical officials casting aspersions on Black Americans, asserting that African Americans frequently exhibit an "irrational" response to healthcare warnings. After the polio vaccine was introduced in 1955, for example, outbreaks of the disease often took place in largely poor and often Black communities. Federal agencies responded, not by investigating the problem, but by accusing poor people of ignoring the call to get vaccinated. However, access to polio vaccines were not readily available in low-income, inner-city communities of color at the time.

In reality, there was very little active "resistance" to the polio vaccine on the part of African Americans. Polio victims in the African American community were a constant, powerful, and invisible reminder of the grave consequences associated with not being vaccinated for that disease. Vaccination access was the bigger problem. As noted earlier, the American medical community did not present itself as a fair distributor of healthcare for people of color.

Health disparities, and the tendency to blame the victims, did not begin in the 1950s with the polio vaccines. Earlier in the 20<sup>th</sup> century, the cases of tuberculosis and other infectious diseases were high in Black communities because there were only a few hospitals that treated African Americans patients, and those that were available seldom provided exceptional medical care, particularly preventative health services. Overcrowding in housing due to racism and poverty also meant that highly infectious diseases like tuberculosis could spread easily. The high infection rates seen in Black communities that resulted from disparities in access were used politically to justify the segregation of the races, although the unfortunate outcomes were the consequence of preplanned inequitable medical care and structural racism in American medicine.

Unpacking the research and medical history of America is the only way to understand African Americans' vaccine hesitancy. Having been the subjects of four centuries of medical maltreatment, apprehensions about COVID-19 vaccines are not without historical foundation. Much of it even traces back to how enslaved African Americans were treated or even experimented upon in the centuries leading up to emancipation.

Much of the discussion of the issues, however, focus on one episode. Perhaps the most disturbing modern example of experimentation on African Americans was the early 20<sup>th</sup> century "United States Public Health Service Study of Untreated Syphilis in Tuskegee and Macon County, Alabama," as it was correctly renamed by descendants of its victims. It had previously been known as the "Tuskegee Syphilis Study." Referring to the experiments as the "Tuskegee Syphilis Study" puts the onus and responsibility for the study on Tuskegee rather than on the USPHS.

### **The Disease**

From the 15<sup>th</sup> through the 20<sup>th</sup> centuries, sexually transmitted infections (STI's) were not uncommon. Author Susan Perry estimated that during the 18<sup>th</sup> century, 20% of Londoners had contracted syphilis before they reached their mid-30s.<sup>23</sup> Many of the afflicted were "young, impoverished, unmarried women" engaged in occupations where sexual predation was common (e.g., barmaids, cooks, maids, and servants).

Patients who contracted syphilis were administered a five-week hospital treatment where they were given large doses of medicines containing arsenic or mercury, which caused excessive salivation. Theoretically, salivating would release the impurities in the body caused by the disease. Some patients received mercury-based treatments for the balance of their lives, leading to the saying: "A night with Venus, and a lifetime with mercury," since mercury comes with significant side effects including mouth ulcers, loss of teeth, kidney failure, mental illness and possibly death.

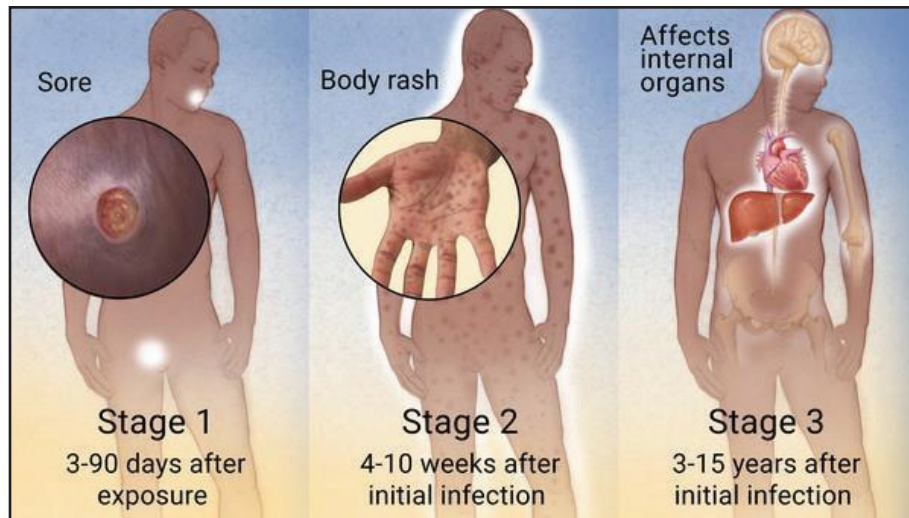
Syphilis is a bacterial infection (caused by the bacterium "Treponema pallidum") that is usually spread by sexual contact or by an infected mother passed on to her baby at birth.<sup>24</sup> Congenital syphilis occurs when a pregnant mother passes the bacterium on to her baby. The disease can also be passed by mother to baby during labor or nursing. Miscarriage rates were universally linked to sexually transmitted infections.

Syphilis is considered a sexually transmitted disease that starts as a painless sore. The disease develops in stages, and its symptoms vary by stage, each of which can cause serious health effects unless adequately treated. Early medical practitioners referred to syphilis as "The Great Pretender," since its symptoms are similar to numerous other diseases. However, syphilis typically follows a progression of stages that last for weeks, months, or even years.

The first stage involves a painless sore on the genitals, rectum, or mouth. After the initial sore heals, the second stage begins, which is characterized by a rash. Next, there are virtually no new symptoms until the final stage which may occur years later or not at all. This final stage often results in damage to the brain, nerves, eyes, or heart.

The standard treatment for syphilis is now penicillin, and one's sexual partners also must be treated. After 1947, penicillin largely eliminated syphilis as a potential health problem in the United States, although the treatment does not always help people with major complications in the latent or advanced stages of the disease.





Researchers have found that Black Americans are the most hesitant to get a vaccine among all racial and ethnic groups. Many vaccine-hesitant African Americans still cite the government-sponsored “Tuskegee Study,” as a primary reason for their vaccine hesitancy. During this experiment, African American men were treated in ways hardly different from laboratory animals. In a May 2020 Pew Research Center study, 54% of Black adults said that they were willing to get the COVID-19 vaccine. By September of that year, that willingness had dropped to 32%. Some skeptics alleged (without evidence other than hearsay) that the new COVID-19 vaccines were “another Tuskegee experiment!” Whatever the main reason was for their hesitancy, the Black acceptance rate for vaccinations plummeted.

### **In the Beginning**

In 1932, Dr. J. R. Heller, Chief of the Venereal Diseases section of the U.S. Public Health Service Department (USPHS), working with the Tuskegee Institute, launched a research project entitled the “United States Public Health Service Study of Untreated Syphilis on Negro Males.” It was conceived under the guise of “observing the natural history of untreated syphilis” in Black populations by tracking the natural progression of the disease without treating those afflicted with this disease. The USPHS justified the USPHSSUSNM study by falsely claiming that it was difficult to convince African Americans to get treatment for syphilis, anyway, making this “a study in nature” rather than an atrocious experiment on live human subjects. It was also assumed by those in charge that the course of the disease would be different in African Americans, whose symptoms were presumed to be primarily cardiovascular complications, while neurological difficulties were the predominant effects of the disease on White Americans.

Over the course of the first few months, researchers recruited 623 impoverished, poorly educated (primarily sharecroppers), African American males in Macon County, Alabama. In that area, an estimated 35% of the population was infected with syphilis.<sup>25</sup> The men unintentionally became part of a long-term study on the health consequences of syphilis, when patients are denied proper medical treatment for the disease. At the onset of the study, the customary treatment was an arsenic and mercury-based treatment with harsh side effects. However, medical professionals were already beginning to have suspicions concerning the effectiveness of these treatments, especially during the third stage of the disease.

### **The Experiment**

The initial study involved 422 men with latent syphilis (the treatment or experimental group – the so-called “subjects”) and 201 with no signs of the disease (the control group). All of the men were between the ages of 25 and 60. At least 12 men in the control group later contracted the disease and were simply switched over to the experimental group.

The African American men involved were never told they were part of a study. It was presented to them as a vague sounding medical program designed to treat their “bad blood,” which, at the time, was a catchall term encompassing anemia, syphilis, fatigue, and various other conditions. The tragic truth was that no plans ever existed for the men to receive any adequate treatment at all, although they were led to believe they were being treated for their ailments. Some were administered aspirins, iron tonics, and vitamins, but never any effective medications to treat their disease. Even diagnostic spinal taps (to test for any neurological complications affecting White Americans) were administered as a “special treatment” for some of the subjects.

For their participation in the study, the men were informed that they would receive free medical care to treat their “bad blood,” including free exams (blood tests, x-rays, spinal taps, etc.), free hot meals, free transportation to and from the hospital, free medical treatment for ailments other than syphilis, and free burial insurance on the condition that they agree to be autopsied at their death. Most people, and especially African Americans, could only dream of such a “generous” list of free services, during the Great Depression. These incentives were a covert method of preventing them from missing their scheduled appointments where more data could be collected.

The unsuspecting subjects were told that the study would last approximately 6 months. Instead, for the next 40 years, the researchers continued investigating the effects of untreated syphilis in these African American men. The only way that the experimenters could determine the full effects of the disease was by withholding treatment and autopsying their bodies following death.

It is significant to note that the USPHS researchers allowed over 423 of the infected men to endure the effects of the disease and its side effects without proper medical treatment, without their “informed consent,” and without informing the men, their families, or their family doctors that penicillin had been found to be an effective remedy.<sup>26</sup> Although the men in the study were supposed to be in the non-contagious stage when the study began (not all of them were), the act of medical negligence allowed the disease to be transferred to their spouses, partners, and children.

Contrary to the folklore, urban legends, and unintentional misstatements that have circulated for decades, none of the 623 men were ever consciously *injected* with syphilis by any government agency. Instead, the men who were merely diagnosed with the disease had been syphilitic for at least five years, and the USPHS teams followed up by meticulously monitoring the effects of the untreated illness. Only a small number of the subjects actually received any medications provided by the agency, but they were given ineffective remedies (capsules and ointments with extremely low doses of mercury) at the beginning of the study.

### **Keeping the Study a Secret**

Several times during the experiment, researchers worked diligently to assure that the subjects (1) remained unaware that they had ever contracted the disease, and (2) did not receive outside medical treatment for the disease. In 1934, the researchers went as far as to provide all local Macon County doctors with a list of the names of the men, and asked local doctors *not* to treat the men for syphilis. In 1940, the researchers sought and received similar cooperation from the Alabama Health Department. Many of the men were suspicious that the actual purpose of the study was not to investigate their “bad blood,” but to recruit them for U.S. military service. Unfortunately, the intentions of the researchers were considerably worse than military service.

At the beginning of World War II, some of the men became eligible to be drafted into the U.S. military. During the routine entrance medical exams, the fact that they were carriers of syphilis might have been revealed. To avoid exposure, the USPHS researchers gave a list of the men to the draft boards to prevent the men from being enlisted, which might have (1) allowed the men to receive life-saving treatment for the disease, and (2) exposed the true nature of the unscrupulous study they unknowingly were a party to. More importantly to the USPHS, denying their enlistment into the military allowed the study to continue.

During the four decades of experimentation, the USPHS examined, evaluated, and watched numerous Black men die what was clearly an avoidable death. By 1947, penicillin had been recognized as a safe, reliable, and effective remedy for syphilis, and the medicine became widely available to all Americans except the Tuskegee study subjects. By then, dozens of men had died. Their wives, children, and untold numbers of other African Americans had been either infected or affected by the disease. Nonetheless, the research project continued since (a) the men were never informed that they had ever contracted the disease, and (b) they were never made aware that a safe remedy for their ongoing health struggles was now available.

By the 1950s, not all of the men were left untreated. Some received penicillin for other ailments, and others had moved away from Macon County. At that point, the USPHS could not control what happened to them medically. By 1952, one third of the men had received penicillin despite the best efforts of the researchers to prevent it. The USPHS claimed that the men were merely reluctant to visit a doctor. However, many did not feel an urgent need to see a doctor, since they had faith that the USPHS was already providing them adequate treatment for bad blood, which would make supplemental medical services redundant.

By the mid-1950s, many of the men in the study had become quite ill, having reached the final stages of syphilis. By the end of the study, Public Health Service records indicated that approximately 128 patients had died of syphilis or its complications. Approximately 40 of their wives had been infected, and 19 of their children had been born with congenital syphilis.

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## Ideas & Trends

# Tuskegee's Long Arm Still Touches a Nerve

By JEFF STRYKER

**L**AST week, as four of the eight remaining survivors of the Tuskegee syphilis experiments gathered at the Shiloh Baptist Church in Notasulga, Ala., a White House spokeswoman promised that President Clinton would soon formally apologize for the Federal Government's sponsorship of that infamous medical study.

What the spokesman did not say was that even though the "Tuskegee Study of Untreated Syphilis in the Negro Male" ended a quarter of a century ago, some blacks, particularly in the rural South, are still experiencing its effects. So great is the mistrust that grew out of the study that it is continuing to interfere with attempts to fight AIDS in certain black neighborhoods.

According to Cornelius Baker, executive director of the National Association of People with AIDS, an organization that lobbied for Mr. Clinton's apology, "many researchers withheld from the infected men what was then the standard treatment — mercury and arsenic compounds. Then, in 1947, when penicillin was found to be an effective treatment for syphilis, it too was withheld.

Federal researchers even went so far as to get local physicians to promise not to provide antibiotics to individuals in the study.

The study limped along for four decades, until Peter Dinklage, a lawyer who had once been an epidemiologist for the Public Health Service in San Francisco, went public. On July 25, 1972, the media turned klieg lights on the study and it was halted immediately. But that was not the end of Tuskegee's ill effects.

Starting in the 1980's, as the AIDS epidemic began to spread, Stephen B. Thomas and Sandra Quinn Crouse, who were working to create AIDS education programs in black neighborhoods, noticed that when they discussed AIDS the topic of Tuskegee arose almost invariably.

What they found was that many blacks, particularly those living in the rural South, believed that H.I.V., the virus that causes AIDS, was deliberately created in laboratories to kill black people; that AZT, an early treatment for AIDS, was a plot to poison them; that condom distribution was part of a Government plan to reduce the number of black births, and that needle exchange programs were designed to foment drug use in minority communities.

In a 1990 poll conducted by the Southern Christian Leadership Conference, 35 percent of 1,936 black churchgoers said they believed that AIDS was a form of genocide.

For many black Americans, this was no surprise at all.

**Body-Snatchers**

At a hearing sponsored by the National Commission on AIDS to explore the "legacy of mistrust" of Government and medicine in minority communities, Mark Smith, chief executive officer of the California Health Care Foundation, told the tales he heard while treating AIDS patients at Johns Hopkins Hospital.

"One woman told me that she had been cautioned as a child to be home by dark because if she weren't those people from Johns Hopkins would snatch her off the street and experiment on her in the basement at night," he said.

"While people may not have believed this story literally," Mr. Smith added, "its widespread repetition is testimony to the gulf between many research institutions and African-American communities."

The story also showed the importance of oral history.

"The Tuskegee story is a central part of childhood lore" in many black communities, says Mr. Baker, of the National Association of People with AIDS. It is "one of the definite things we were told by our grandparents."

As the story of Tuskegee was passed along, by word of mouth and even in print, exaggerations crept in. Some published accounts erroneously maintained, for example, that the men in the study were intentionally infected with syphilis (as if the Government's failure to offer known treatments were not egregious enough).

Dr. Thomas, who is now the director of the Institute for Minority Health at Emory University's Rollins School of Public Health, believes that the legacy of Tuskegee has interfered with efforts to prevent and treat AIDS.

He accuses the Nation of Islam, which has promoted AIDS treatments of highly dubious efficacy, of "demagoguing" the issue and "playing the Tuskegee race card."

The Tuskegee legacy reverberates well beyond medical research and AIDS, Dr. Thomas says. He believes Tuskegee is a key reason why blacks "are less willing than whites to donate blood, or to become organ donors or to have their children vaccinated."

**The Cost of Suspicion**

The living victims of Tuskegee range in age from 87 to "somewhere between 100 and 99" according to their lawyer, Fred David Gray, and they have already been paid money damages. An out-of-court settlement in a 1974 yielded \$37,500 for each "living syphilitic" and \$15,000 for the heirs of "deceased syphilitics."

But the costs of suspicion have yet to be counted.



Credits for Sources Center

The study of untreated syphilis in black men, which ended 25 years ago, may prompt a Presidential apology.

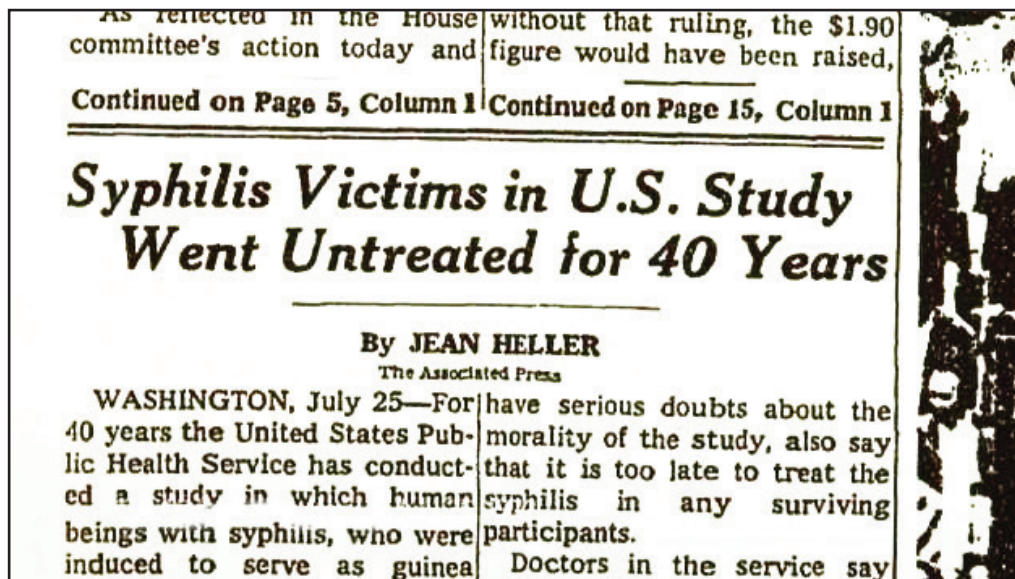
Heart failure claimed the lives of another 154 of them, which could possibly have been caused by the disease. For many others, it was too late for effective treatment. Administering massive doses of penicillin can constitute a health risk to patients, although it is still recommended as the most effective remedy for any stage of the disease.

The Nuremberg Code was published in 1947 as a result of the Nuremberg trials of Nazis agencies that had experimented on Jewish people imprisoned during WWII. The Code is a set of ethical research principles that all countries should adhere to during human experimentation. Reinforcing the Nuremberg code, in 1964, the Declaration of Helsinki was released by the World Health Organization, and it became the cornerstone document on human research ethics. Both were designed to protect people from unprincipled experimentation.

Despite these internationally recognized guidelines, the study continued for almost another decade. By then, the Centers for Disease Control had taken control over the study from the USPHS in the late 1960s. Most doctors, even those who were involved in the study, thought only “barbarians” or “Nazis” did terrible things to patients, and they did not believe these codes applied to them.

### **From Shame and Trauma to Honor and Triumph**

On July 25, 1972, Jean Heller, an Associated Press reporter, broke the USPHSSUSNM story of the forty-year-long inhumane “Tuskegee Syphilis Study.”<sup>27</sup> In November of 1972, the New York Times ran a front-page story on the study based on information provided by whistleblower, Peter Buxton, who leaked information to the newspaper. Approximately 128 patients had died of syphilis or its complications. Forty of their wives had been infected, and 19 of their children had been born with congenital syphilis.



The public was shocked, and by that date, there were only 74 surviving members of the entire study. At least 28 of the study’s unsuspecting participants were suffering the last stage of syphilis: organ failure and ultimately death. The revelation of the study took place during the era of the Watergate scandal and its subsequent presidential cover-up, along with numerous other political outrages exposing corrupt government practices. The degree of distrust in political leaders had not been seen in generations, which resulted in a national distrust of nearly anything considered government related.

There was public and bipartisan political outrage that an atrocious experiment on human guinea pigs had taken place in the United States unreported and unnoticed for decades. Sen. William Proxmire, a member of the Senate Appropriations Subcommittee, which oversaw the Public Health Services budgets, called the study “a moral and ethical nightmare.” The chilling effects of this research study lingers to this day and likely contributes to COVID-19 vaccine hesitancy.

As a response to the 1972 public anger, the U.S. Assistant Secretary for Health and Scientific Affairs convened an Ad Hoc Advisory Committee comprised of nine experts from the fields of health administration, medicine, law, religion, and education, to review the USPHS study. The

panel concluded that the experiments were “ethically unjustified” and that the “results were disproportionately meager, compared with the known risks to human subjects involved.” In November 1972, a formal end to the study was announced by the US government. The few survivors at that time were too old for any promising treatment, although those willing to take it were given penicillin.

As a sign of overdue decency, in March of 1973, the U.S. Secretary for the Department of Health, Education, and Welfare (HEW) instructed the USPHS Department to provide all necessary medical care for survivors of the study, including the wives, widows, and children of the 623 men through the “Tuskegee Health Benefit Program.” Later, it became a health program, which meant the federal government also paid for home health aides or nursing homes for these survivors.

It is incredible that such an unethical experiment could have ever been proposed and approved by public health officials, and secretly conducted for four decades. It was exclusively for research “curiosity,” since the medical knowledge gained from the study was extremely modest. Despite the outcry concerning the study when more than a dozen reports about it were published in medical journals written by several medical professionals, the study was allowed to continue freely since no one in the medical community questioned the ethics of the study. In the publications, the men were referred to as “volunteers,” concealing the fact that they had never volunteered in any sense at all. The second and less known purpose of the study was to provide syphilitic blood for the USPHS blood bank for commercial sale.



**Ms. Lillie Head-Tyson, a descendant  
of the USPHS syphilis experiments**

Ms. Lillie Head-Tyson is a surviving daughter of Freddie Lee Tyson, who was among the 623 men recruited for the *United States Public Health Service Study of Untreated Syphilis in Tuskegee and Macon County, Alabama*. In addition to her father, Ms. Tyson’s great uncle and two cousins also became part of the experiment. “My father was approached and told he had bad blood,” unaware that he was about to become part of one of the longest unethical studies ever conducted in the United States. It was not until four decades had passed that the Tysons and hundreds of other Black families from Macon County learned that their loved ones had been part of a heinous medical experiment that had started in 1932.



**Freddie Lee Tyson, one of the African American men involved in the USPHS study**

Freddie Lee Tyson had congenital syphilis, although he never showed any symptoms. His daughter reported that he remained healthy and active until he died in a car accident on his way to work at age 82. Ms. Tyson Head shared her story and message at the annual convention of the California Association of African American Superintendents and Administrators in 2022.

Today, she continues to educate the nation about the USPHS study and the importance of medical ethics through the Voices For Our Fathers Legacy Foundation dedicated to understanding the “Tuskegee Experiment” by “transforming the United States Public Service Syphilis Study from shame and trauma, to triumph and honor.”<sup>28</sup> “Despite what some people now think, the men at Tuskegee were not injected with syphilis,” she says, referring to an urban myth circulated throughout the African American community concerning that detail of the experiment. “The whole point was that they were denied available treatment. We are not being denied the vaccine for COVID-19 , so let’s not deny it to ourselves.”

Even though the USPHS study ended more than 50 years ago, African Americans in the rural South and elsewhere in the nation are still feeling its effects. Their mistrust in government-sponsored health recommendations remained at such a high peak that it interfered with fighting AIDS in Black neighborhoods during the 1990s. The myth circulating at that time was that the U.S. government had *produced* HIV in laboratories to deliberately decimate the Black population in the U.S. – a form of genocide.

Today, the Tuskegee legacy still haunts us and produces vaccine hesitancy in the African American community in the midst of the COVID-19 pandemic.



### **Apologies and Reparations**

In 1973, a class action lawsuit was filed on behalf of the 600 African American men. Less than two years later, an out-of-court settlement was reached for approximately \$10 million on behalf of the subjects and the descendants of the USPHS syphilis experiments.

Another two decades passed before President Bill Clinton issued an official apology on behalf of the U.S. government for its role in devising and perpetuating the Tuskegee study, as well as for the deception and medical mistreatment of the men subjected to the experiments. As part of the formal proceedings, Clinton announced a grant initiative to establish the National Center for Bioethics in Health Care and Research at Tuskegee University in Alabama.<sup>29</sup>

Between 1935 and 1972, the Milbank organization had provided funds to support the promise of burial insurance in exchange for a family's willingness to allow the autopsies. In October 2021, Christopher Koller, the president of the Milbank Memorial Fund, along with Samuel L Milbank, the fund's Chairman, issued an apology to the "Voices of Our Fathers Legacy Foundation" on Behalf of the Board of Directors of the Milbank Memorial Fund.<sup>30</sup>

In 2001, the President's Council on Bioethics was established to advise the U.S. President on ethical issues ranging from stem cell research to nanotechnology. This council provides us with greater assurances that experiments similar to the *United States Public Health Service Study of Untreated Syphilis in Tuskegee and Macon County, Alabama* will never occur again inside the borders of the United States.

The positive legacy of the sacrifice of the men is that today, experimental medicine and all clinical trials today are highly regulated to assure (a) ethical procedures and practices, (b) safety, and, (c) that we address diversity, equity, and inclusion in science and medicine. Experiments in any way comparable to the USPHS syphilis study would be impossible today with the creation of Institutional Review Boards (IRB) for science and medicine. IRBs review and assure "in advance" and by "periodic review," that appropriate steps have been taken to protect the rights and welfare of human subjects participating in any research. A further safeguard against abuse of participants in research studies is the requirement for to obtain informed consent from any participant in research projects.

### **US Public Health Services Study: Resources**

- A timeline of significant events surrounding the *USPHSSUSNM* study.  
[https://www.milbank.org/wp-content/uploads/2022/04/Timeline\\_final\\_2.pdf](https://www.milbank.org/wp-content/uploads/2022/04/Timeline_final_2.pdf)
- “An Opportunity of This Kind; the Milbank Memorial Fund and the US Public Health Service Study of Untreated Syphilis in Tuskegee.” Dr. Susan Reverby’s Report to the Milbank Memorial Fund. (April 2022).  
[https://www.milbank.org/wp-content/uploads/2022/06/Reverby\\_report\\_4.24\\_final.pdf](https://www.milbank.org/wp-content/uploads/2022/06/Reverby_report_4.24_final.pdf)
- Apology Letter From The Milbank Memorial Fund. (October 5, 2021).  
<https://www.milbank.org/wp-content/uploads/2022/04/Letter-to-VFOF-Oct-2021.pdf>
- The Official “White House Apology for the Study Done in Tuskegee” from the US government. President Bill Clinton. (May 16, 1997).  
<https://clintonwhitehouse4.archives.gov/New/Remarks/Fri/19970516-898.html>
- Transforming the Legacy from Shame and Trauma to Honor and Triumph: Milbank Memorial Fund’s Public Apology (*video* from event at Tuskegee University).  
<https://www.youtube.com/watch?v=vHg0iyx07W4>
- Tuskegee Legacy Stories: COVID-19 Vaccine Education Initiative – “As COVID-19 puts a spotlight on public health, future generations from Tuskegee are working to build back trust” (*video*).  
<https://getvaccineanswers.org/Legacy>
- The *Voices for Our Fathers Legacy Foundation*.  
<https://www.voicesforfathers.org/>

**Authors’ note:** The “Voices for Our Fathers Legacy Foundation” offers a scholarship to deserving students. Applicants must be descendants (directly or indirectly) of one or more participants in the United States Public Health Service Syphilis Study conducted in Tuskegee and Macon County, Alabama. For more information on this scholarship opportunity, please see the website below.

<https://www.voicesforfathers.org/>

### **Question #3:**

**How can we reduce vaccine hesitancy among our peers, friends, and family members in the African American community?**

When sheltering-in-place became mandatory in California and many other states, the “new normal” grew very old, very quickly. We all began asking one another, “How long will this lockdown last?” Equally important, given the grave predictions about how lethal the coronavirus appeared to be, we also asked, “What must I do to keep myself, my family, my friends, and my loved ones safe and



alive?” It was evident that there were methods that could increase (but not guarantee) one’s safety from contracting COVID-19. Those methods included avoiding crowded spaces, recognizing social distances, taking advantage of any nearby hand sanitizer, wearing a face mask indoors, etc., to avoid exposure to the coronavirus or spreading it. Adopting these measures indeed provides additional layers of protection from the disease.

While many members of the African American community have moved from being “vaccine hesitant” towards joining the “accept all vaccines and boosters” category, it is our hope that we will reach both herd immunity and general COVID-19 vaccination acceptance for all African Americans.

Nearly everyone would answer affirmatively to the following questions. We must also make certain that everyone in the Black community understands the gravity of any answer other than a strong affirmative response to every question.

- Do you want to protect your loved ones?
- Do you want them to live a long healthy life?
- Would you protect them from a fire?
- Would you try to save them in a flood?
- Would you protect them from a deadly disease if you could?

By getting your COVID-19 vaccinations and booster shots, you are protecting those closest to you -- your friends and loved ones. Just as important, making sure that *they* are up to date on their vaccines will protect them from COVID-19 by the most effective method currently in existence. A Los Angeles mother summarized the seriousness of this vaccination concisely by saying, “I would rather *get* the vaccine than to *bury* one of my children or to have them bury me!”

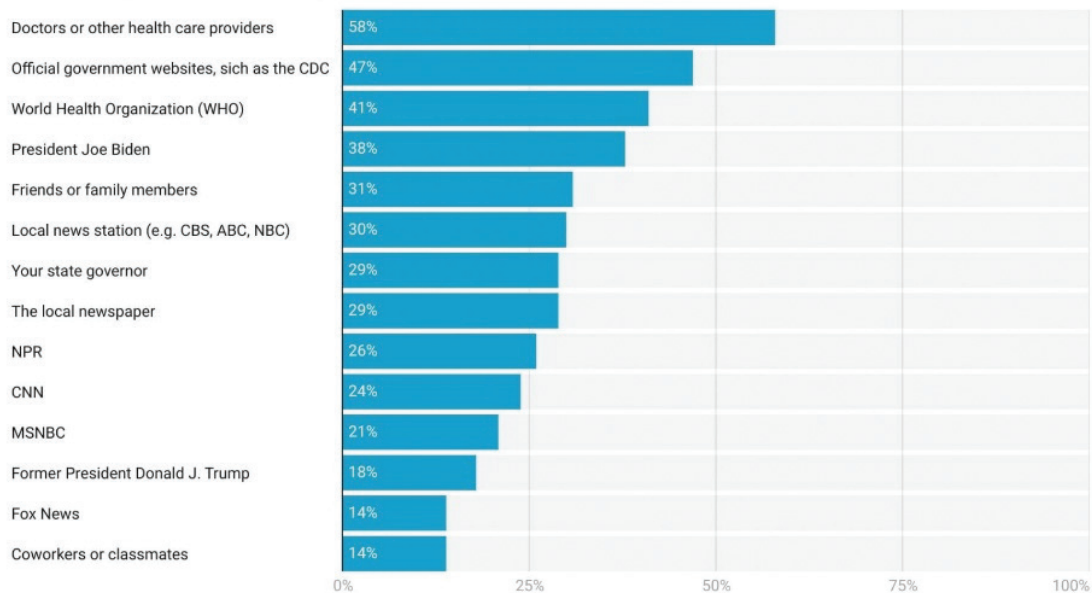
Every community in the world assesses its local dangers and prepares responses to possibly hazardous and life-threatening events that can result in a massive loss of life. As a result, every organized society has fire departments, emergency responders, departments in charge of water resources, etc., that respond to crises before they become an insurmountable event. This approach is how the human species has survived over the millennia. The coronavirus can be as deadly as a hurricane, tornado, or tsunami. Fortunately, there are measures that we can take to protect ourselves, including the information that appears below.

### **The Most Trusted COVID-19 information sources:**

In our earlier discussion about misinformation, disinformation, as well as being *uninformed* due to a lack of information (or not reading the available information), we stated that collectively there are avoidable dangers of COVID-19. Among the best resources for trustworthy information are the following:

- Research from the Kaiser Family Foundation, which has found physicians, pediatricians, and healthcare providers to be the most trusted source of information on the COVID-19 vaccine. (Over 77% of parents consider these sources to be most trusted for dependable information on coronavirus and COVID-19 vaccines.)
- Regardless of race or political affiliation, **peditricians** are seen by parents as the most trustworthy source of vaccine information.
- Local hospital or public health departments
- Printed information sent home by teachers and administrators. (Almost 50% of parents say their child’s school has provided them with information about how to get a COVID-19 vaccine for their child). Parents who report that their child’s school has encouraged them to get their children vaccinated are more likely to say their child has indeed gotten vaccinated. Those parents are also four times as likely to get their child vaccinated.
- Medical organizations, healthcare associations, and the Centers for Disease Control and Prevention.

## Trusted (Mostly or Completely) for COVID-19 Information



Source: Tufts Equity Research Group

- **Information sources to consciously avoid include:**
  - Internet blogs
  - unsolicited “shares” on Facebook
  - random “tweets” from Twitter
  - unrequested messages from Instagram

It should be noted here that social media platforms are designed with algorithms that “give you more of what you’re looking for.” Search engines were devised to augment your initial request with a stream of similar information (including disinformation). More importantly, if a particular bias (positive, negative, partisan sentiment, etc.) or slant is suggested by the websites you seem to “explore,” you will be directed towards still *more* sites of the same genre expressing the same sentiment.

The greatest danger in this search engine formula is that individuals spend hours on the Internet and begin to conclude (with reason) that the massive amount of information they have seen continues to confirm their existing beliefs and appears to represent a majority opinion or at least “the norm.” People who have followed this path can be easily detected, when they begin their statements about COVID-19 with, “Everyone knows...” or “Everybody says...” These individuals fill the ranks of the “refuse all vaccinations” group that represents the 20% of the population that refuses to be vaccinated. Most unfortunate, “fact-checking” exercises to them means returning to the same Internet sources for “fact-free” information (a.k.a., “alternative facts”) where they gather information that is not grounded in evidence-based reality.

An important description of this behavior comes from the field of psychology, and it may help explain this kind of thinking. The term is “confirmation bias,” which is the tendency to look for information that supports the information that an individual already believes. It also describes the tendency to seek new information that confirms one’s existing beliefs, and the rejection of any contradictory information, which is deemed false or “fake news.” We all want to be “right,” and we gravitate towards information that proves that we indeed are correct.

Information that challenges or contradicts a firm belief we hold is often quickly dismissed (sometimes with a hint of hostility), while supportive “facts” are always welcomed. You will notice how strongly and quickly people will agree with statements that support their current beliefs. Misinformation is best “replaced” or substituted with information an individual finds acceptable, which can “fill in the gap” left by information supporting a belief they suddenly realize is inaccurate.

Every belief system has a foundation. To unseat an existing belief, the foundation supporting the belief (the facts, evidence, opinions, etc.) must still be reinforced, but it will occur with *new* information, facts, data, or anecdotal stories that are considered acceptable substitutes for building a new “belief foundation.”

COVID-19 has been a part of our lives for over three years, and so has the barrage of misinformation, myths, and misleading information about the virus. Some are silly and outlandish, while others are downright dangerous when believed. One study found that 78% of the public believes or is unsure about at least one false COVID-19 statement or myth, and over 30% believe at least four of eight false statements when they were surveyed. Finding misleading information is easy, and much of it comes to us unsolicited. Twitter terminated the enforcement of its COVID-19 misinformation policy, which opened the floodgates to more COVID-19 misinformation. An Australian research team collected more than half a million conspiratorial and misleading English-language tweets about COVID-19 that were retweeted over a half million times with more than a million and a half “likes.”

### **The 55 Most Popular Myths About COVID-19**

Below are the 55 most commonly shared inaccurate statements about COVID-19.<sup>31</sup> (They have been organized into six general categories). In addition to being erroneous, many of the statements (misinformation, disinformation, and some recycled bogus news) are completely without medical, factual, or even logical foundation. Sadly, they seem to “go viral” much faster than accurate and factual information does. Keep in mind that those who hold these beliefs do not abandon them easily.

#### ***The Government:***

1. The government is exaggerating the number of COVID-19 deaths.
2. COVID-19 deaths are being hidden by the government. (Contradicting the previous statement, but strangely, some individuals claim that both statements are true!)
3. *COVID-19 is a man-made disease.*
4. The novel coronavirus was engineered in a lab in China.
5. Wealthy elites intentionally spread the virus to gain more power and profit.
6. Spikes in *COVID-19* cases occur because of increased government testing.
7. Hospitals are purposely misdiagnosing and treating patients for *COVID-19* because doctors get paid extra for treating coronavirus patients.
8. 5G technology caused the coronavirus.

#### ***Coronavirus Immunity:***

9. *If we let as many people as possible catch the virus, we would all be immune, and there would be very few deaths in the short-term.*
10. Children do not need to be vaccinated because they develop their own immunity.
11. Natural immunity is comparable to a *COVID-19* vaccination.
12. Herd immunity will end the coronavirus pandemic, so vaccinations are not really necessary.
13. We can achieve herd immunity by letting the virus spread through the population.
14. Natural immunity is healthier and more effective than vaccine-induced immunity.
15. *COVID-19* vaccines cause immune system damage.
16. Safety precautions aren’t necessary because *COVID-19* treatments are widely available now.
17. Getting a *COVID-19* vaccine means I can stop wearing my mask and taking coronavirus precautions.
18. If I’ve already had *COVID-19*, so I don’t need a vaccine.

#### ***COVID-19***

19. Children can’t get *COVID-19* .
20. *COVID-19 only affects older people, so young people don’t have to worry about it.*
21. The Black Lives Matter protests led to increased transmission.

22. COVID-19 is no worse than the flu.
23. Deliberately exposing yourself or your child to the coronavirus to get it over with, is a good idea.
24. Obesity kills more people than coronavirus.
25. *If you have COVID-19 and aren't showing symptoms, you won't transmit the disease.*
26. *We don't need to worry about another wave of COVID-19. It's the same as the normal winter cold and flu season.*

### **COVID-19 Tests**

27. Getting tested for COVID-19 is expensive.
28. COVID-19 tests cannot tell the difference between the flu, colds, or the coronavirus.
29. COVID-19 testing is inaccurate and the tests have "false positives" of 80%.

### **The Vaccines:**

30. A vaccine to prevent COVID-19 is unavailable at this time.
31. COVID-19 vaccines are still unproven and unsafe.
32. Researchers rushed the development of the COVID-19 vaccine, so its effectiveness and safety cannot be trusted.
33. Because the vaccines work, I don't need boosters.
34. The vaccine does not work against the Omicron variant.
35. COVID-19 vaccines will alter my DNA.
36. Having COVID-19 gives you better protection than getting the vaccine.
37. People who receive the COVID-19 vaccine get serious side effects.
38. You can safely delay getting a COVID-19 vaccine until the coronavirus pandemic is over.
39. Vaccines can overload your immune system.
40. If everyone around me is immune, then I don't need to be vaccinated.
41. The flu vaccine protects you against COVID-19 also.
42. Vaccines can cause autism.
43. A booster dose of the COVID-19 vaccine isn't really necessary.
44. Getting COVID-19 vaccinations is very costly.
45. COVID-19 vaccines can cause kidney failure.
46. The side effects of the COVID-19 vaccine are dangerous and sometimes deadly.
47. The COVID-19 vaccine was developed with controversial substances like fetal tissue.

### **Remedies:**

48. Ivermectin (a medicine that controls parasites in animals and humans) cures or prevents COVID-19.
49. Warm water or saline will protect you from getting sick if you're exposed to the coronavirus.
50. You can get a face mask exemption card, so you don't really need to wear a mask. (*Note: no such exemption card exists at*).
51. Urging high-risk people to stay home and letting everyone else live normal lives would "solve" the crisis.
52. Hydroxychloroquine is an effective COVID-19 treatment.
53. Masks don't really work to protect a person from getting COVID-19 .
54. Face masks are harmful to your health and can even kill you.
55. You can protect yourself from COVID-19 by injecting, swallowing, bathing in, or rubbing onto your body bleach, disinfectants, or rubbing alcohols.

Most parents have heard a majority of the above 55 reasons that cause them to lean towards vaccine hesitancy. Just as important, these reasons cause confusion for parents who want to make the best decision for themselves as well as their children, but they are inundated with misinformation.

Although many of the above statements are not grounded in fact, they nonetheless serve as reasons for vaccine hesitancy. Fortunately, the ranks of the unvaccinated are shrinking. Unfortunately, they still represent a sizeable health threat to everyone around them.

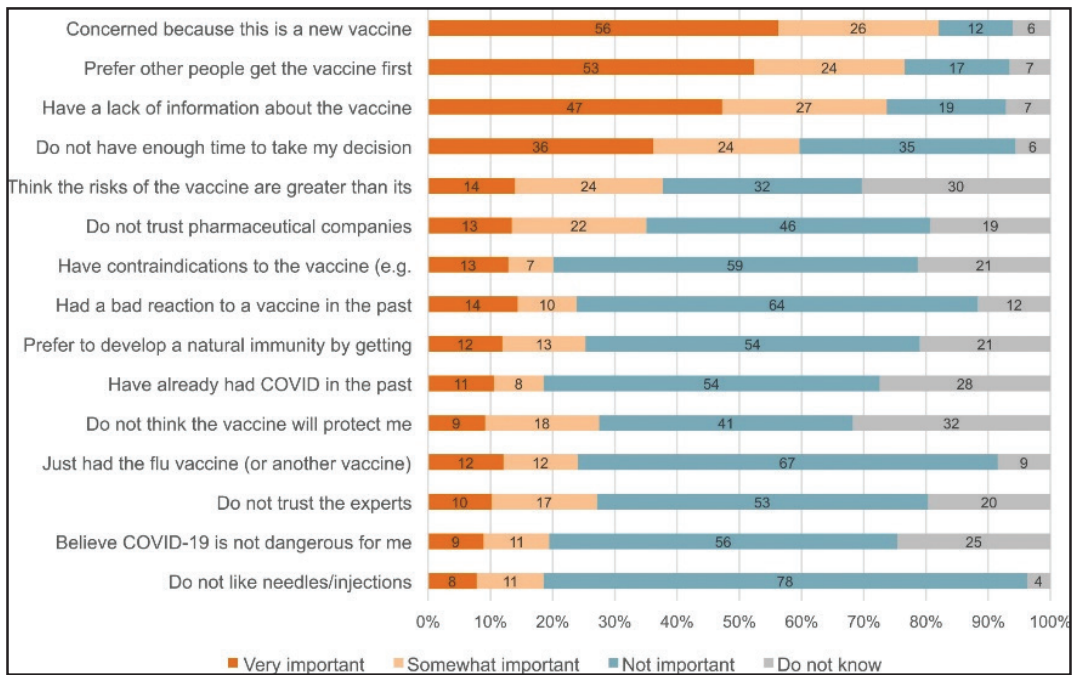
## How to Answer Coronavirus Questions

Several of the most prevalent attitudes, beliefs, and statements from the unvaccinated are reflected in the following (with responses worth remembering and using in conversations with individuals expressing them):

1. “The vaccine is too new.” **(Response:** Yes, and hopefully, you won’t be *dead* by the time it’s considered “old.” While the vaccine itself might be newer, the mRNA technology has been around for decades and is not new. The vaccine has been proven to be safe and is cost-free.)
2. “The vaccine hasn’t been tested enough.” **(Response:** COVID-19 vaccines went through all the same research and testing that every other vaccine has had to go through, they were just not tested for *longer* periods of time than some other vaccines.)
3. “There still are safety concerns and possible side effects including long-term COVID.” **(Response:** The risk of long COVID and other long-term effects are far greater after becoming infected with COVID-19 than after vaccination. All of the customary safety protocols were met in the development of COVID-19 vaccines.)
4. “You can get COVID-19 from the COVID-19 vaccine.” **(Response:** The vaccines do not contain *live* coronavirus, and you cannot and will not get COVID-19 from a vaccination. The vaccine will not *cause* the disease that it was designed to prevent. The chances of dying from or needing hospitalization from a COVID-19 vaccination is near zero.)
5. “There are potential side effects to the vaccine.” **(Response:** Side effects are common to any medication including cough syrup, vaccines, or even a routine dental procedure. These side effects tend to be mild. “Caution fatigue” opens the door to resistance and vaccine hesitancy.)
6. “My kids did not get their other immunizations (there are just too many, and they come too often) and they didn’t get sick. So, I probably don’t need this vaccine either.” **(Response:** Because most children are immunized against the common diseases listed earlier, we have reached herd immunity which gives them added protection. Herd immunity has not been achieved for COVID-19. By getting vaccinated, you are not only protecting yourself, but you are protecting everyone around you (family, friends, and anyone who comes into contact with you).
7. “You can still get COVID-19 even if you’ve been vaccinated.” **(Response:** Yes, the COVID vaccines protect against the worst outcomes of COVID-19 illness. Although the most recent booster has shown to prevent infection, it is still possible to be infected with COVID-19 after vaccination. Vaccines protect you from winding up in the hospital and death from COVID. If you are vaccinated, you are much less likely to get a severe case of COVID-19 or to transmit it to others.)

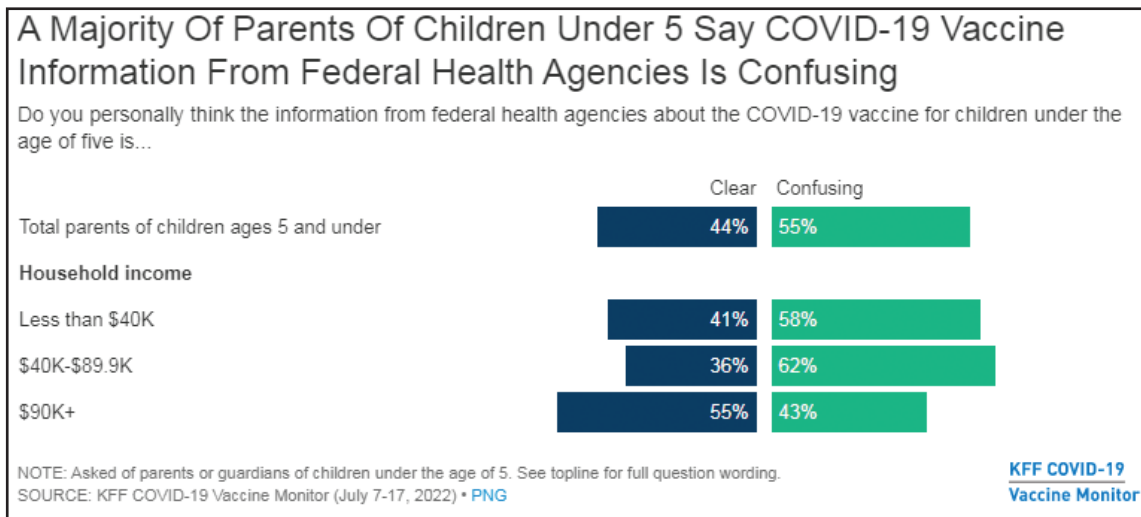
One popular claim by the vaccine hesitant has been that the COVID-19 vaccine was developed too quickly to be safe.<sup>32</sup> Once the magnitude of the global pandemic was internationally acknowledged, unlimited resources and funds were channeled into finding a cure to the pandemic and ending the crisis. The development of COVID-19 vaccines did not include cutting corners on safety or effectiveness, although the traditional amount of time to evaluate long-term (3 to 5 years and more) side effects was abbreviated. However, every vaccine available today was thoroughly tested by every other traditional evaluation procedure. By October 2022, over 613 million doses of the COVID-19 vaccine had been administered throughout the U.S. at a rate of over 30,000 per day with few reported side effects.

The seven sentiments above have contributed to increases in the “wait-and-see” group below.



The social media platform, TikTok, removed more than 250 videos from its platform due to their high level of COVID-19 falsehoods. The greatest danger of this misinformation is that it not only *increases* vaccine hesitancy, but it also *decreases* the number of people who are willing to visit doctors when they begin displaying symptoms COVID-19 or any other disease. It is most important that misinformation be countered by accurate information and facts, many of which are contained within this handbook.

The chart below provides one picture of the confusion that parents encounter even when they are examining literature and information provided by government-sponsored health agencies.



A wealth of information and misinformation about COVID-19 is readily available on the Internet, but the “online availability” is by no means a testimony to its accuracy. Information need not be fact-based, or fact-checked before being posted. Since the credibility of a source or a fact is not always easily determined, using the SHARE checklist below can help you avoid becoming another source spreading useless or harmful content.<sup>33</sup> (This information was excerpted and revised from the United Kingdom).

- **Source:** Rely on official medical and healthcare sources for safety and vaccination information.
- **Headline:** Headlines do not always tell the full story. Always read to the end of an article before sharing it with others.
- **Analyze:** Evaluate the facts. If something sounds unbelievable, it very well could be. Independent fact-checking services are correcting false information about coronavirus every day, but they cannot keep up with the sheer volume of information posted online.
- **Retouched:** Watch out for misleading pictures and videos in stories about coronavirus. They might be edited, photoshopped, or show an unrelated place or event. Check to see who else is posting the information or using the photo.
- **Errors:** Look for mistakes, typos, grammatical errors, and other mistakes that suggest the information was written by a nonprofessional source, was carelessly written, incoherent, or poorly written. Content found on websites that are maintained by medical, hospital, research or government organizations will usually be coherent, well organized and well-written. The content will usually be accurate, documented, referenced, and carefully checked by multiple expert sources before posting.

### **How Do I approach family members or friends who are vaccine hesitant?**

According to research findings from the Nielsen Corporation, a data retrieval and analysis organization, African Americans are 37% more likely than others to say they are influenced more by word-of-mouth recommendations. Each of us has personal experiences that tells us that word-of-mouth information, and particularly health information, might not always make its way through the Black community without the facts, details, and conclusions getting “reworked” by each author as the information is retold. One of the purposes of this handbook is to make certain that students, teachers, parents, and community members have at least one detailed and evidence-based handbook that can be shared with others either online or in printed form.

The reasons behind vaccine hesitancy are varied, complex, and involve more than just a knowledge deficit. If you are uncertain about how to begin a conversation with vaccine hesitant friends or family members (or other “vaccine skeptics”), you are not alone. We are all cautious about telling people things that they might find difficult to hear, particularly people we consider close to us. However, working strongly in your favor is the fact that it is much easier to listen to people who we like, than it is to hear anything from someone who we dislike.

When the “messenger” conveying the information is someone who the listener (whether it is just one individual or a large audience filling an auditorium), trusts, likes or finds likable, sees as competent, caring, and credible, it is at least *more likely* that the message will be heard, assessed fairly, and evaluated in ways that might lead to a change in thinking about COVID-19 vaccinations.

### **What are the elements of a productive vaccine hesitancy conversation?**

Getting family members and friends to move from “I’m just not sure” to “Yes, I’d better get vaccinated soon,” requires special assets that you already have in your favor.

Research on effective communication informs us that the credibility of the messenger is one of the most important factors in getting any information to be accepted by others. Equally important is the personal-emotional connection that the messenger has with the listener(s). Thus, one of the most effective strategies for changing the minds of people who might be vaccine hesitant is the “credible colleague approach.” That technique emphasizes both the credibility the messenger has, as well as the personal connection the messenger has to the listener(s) regardless of the size of the audience.

If you are not the credible colleague, invite someone else to participate with you in a conversation with a vaccine hesitant friend or family member. Some people have been overwhelmed by the massive amount of information bombarding them and just need someone to help sort it out and identify the information most important for final decision-making.

Dr. Margaret Day, MD at the University of Missouri Health Care recommends a version of these three (edited) strategies:

1. Start by listening to the **reasons behind their hesitancy**. Do not turn the conversation into an argument or confrontation where they feel they need to defend their position. People often are willing to change their beliefs based on new information that they were not aware of previously. Very seldom are people “shamed” into believing differently, but they can be coaxed. You will need the other person’s buy-in before they will change their mind.
2. Cite **the long successful history of vaccines** and how they have improved human health worldwide and in the United States. Some people are most in need of overcoming their deep-rooted fear and skepticism.
3. **Address misconceptions** by focusing on the pertinent facts and the related evidence rather than arguing the merits of the rumors and misinformation. Dispelling misinformation and conspiracy beliefs can be important, but it requires substituting their misinformation with accurate information from sources that they agree are credible.

### Motivational Interviewing

A strategy called “motivational interviewing,” recommends that you follow the five important steps in the illustration below. One of the most important steps is to be an open and honest listener to the concerns expressed by a vaccine hesitant person. Their anxieties may center around (a) fear of doctors, hospitals, or needles, (b) confusion from the vast amount of information and misinformation that interferes with making a final and firm vaccination decision, or (c) no one has walked them through the process of making a decision that they can be comfortable with yet. This is where you come in to play a role that can possibly save their life.



Open the “motivational interviewing” conversation with an open question like, “Can you help me understand why you feel...?” It is also important to follow-up during the conversation with richer questions that allow them to examine their own thinking including questions like, “Do you recall where you got that information from?” Whatever questions you present, present them calmly, patiently, and with kind concern rather than an argumentative attitude with negativity, disrespect, or contempt. When the conversation has been very confrontational, it frequently prompts individuals to “dig in” deeper to justify their feelings or their behavior.



## **Strategies for Open and Productive Vaccine Hesitancy Conversations**

Strategies that help keep the vaccine hesitancy conversation open and productive include the following:

- **Come to the discussion with your facts in hand.** (This handbook may be useful during the conversation as a reference tool and helpful to leave with them). Communicate with confidence.
- **Keep the conversation positive.** Approach them as a friend, not a debate opponent. Talk about the excitement you've seen in others because they are relieved from having gotten all of the vaccines for themselves and their family members.
- Ask **open-ended questions** and then ask pertinent follow-up questions. (This also shows you are truly listening). Example: "With what you have told me so far, if there was one thing that could help you change your mind about getting vaccinated, what would that be?"
- **Listen first, speak second.**
- Be **genuinely interested** in their answers to any questions you pose, rather than thinking about your next question. **Do not get sidetracked with extraneous negative topics.**
- Give them **your undivided attention** in a one-on-one conversation. Maintain eye contact as best you can. Human-to-human connections depend on where your attention seems to be focused. Do not multitask – do not look at your phone or keep checking for messages from others during your conversation.
- The **"walk-and-talk"** conversational strategy is effective. While walking, we send 10% more glucose to the brain, which provides more energy for thinking. Our bodies were designed to move, so walking and talking are natural and enjoyable ways to improve communication, which sets the stage for a productive "vaccine hesitancy" conversation. (Enjoying a cup of coffee during the conversation is another way to make the discussion an active and positive experience.
- Listen with an **open mind**.<sup>34</sup> Opinions and emotions play an important role in vaccine hesitancy. Everyone wants to be heard even when they are in the process of changing their minds! *Their feelings* are just as valid and important to them as *your facts*.
- Avoid making negative or distracting **facial expressions**. Keep your composure no matter what they are telling you. Be aware of your body language (do not fold your arms across your chest, roll your eyes, frown and interrupt, etc.), which can interfere with maintaining rapport.
- Show **empathy**. Ask questions that reflect your respect for their fears and feelings. Avoid any hint of sarcasm.
- If they have questions and you don't know, **say you don't know**. However, be sure to tell them that you will find out or help them find the answer.
- It is important to plan points during the discussion when you will deliberately **talk less and listen** more during the conversation. This demonstrates that you care about hearing what they have to say.
- When they say something positive or sound like they are moving away from their vaccine hesitancy, smile and nod positively.
- Keep the focus on the short-term as well as the long-term benefits that being vaccinated will have for everyone around them.
- Don't equate **their life experiences** with yours, suggesting that they should have gotten the vaccine long ago, because you did.

- Do not **demean or degrade** the other person. Try not to be judgmental. The dialogue can quickly shift from vaccine hesitancy to how you are mistreating the other person.
- If they describe some unique challenges that have led to their vaccine hesitancy, **acknowledge them** without saying their challenges are legitimate or illegitimate. Do not get into the contest of whose challenges are greater.
- Misinformation or distorted facts that you may find silly may be something they truly believe. Feeling that you have **shamed them** or that you have judged them will not move their decision-making needle. It will just be the end of your conversation.
- Avoid giving them answers or explanations that are long-winded or begin to sound like a **lecture**. Do not pontificate. Try not to repeat yourself unless you are answering a question of theirs for the second time. Conversations should be two-way, two-person experiences.
- **Storytelling** is powerful. If you are aware of a relevant positive story that helps make your point, share it with them. Stories can be eye-opening, captivating, and motivating.
- If your family member or friend begins to get **angry or upset**, ask them, “Would you like to talk about this at a different time?” Never make them feel “trapped” into participating in the conversation.
- Let them know that **you are a resource** for them if they would like to talk more about ending their vaccine hesitation.
- **Jointly Summarize** your conversation with their input and plan a time to have a final conversation on vaccine hesitancy together.
- If they express an interest in finally **getting vaccinated**, ask them when you can follow up with them, and how you can help them with their “next steps” as soon as possible.

It is most important that you keep the channels of communications open to keep the conversation flowing. That is the only way to understand the specific worries that initially generated their hesitancy or maintained it. If they have not committed to getting vaccinated, continue engaging them regularly with additional new information (“I thought you might be interested in seeing this article/website. You’ll find that it adds to the conversation we had.”) Be supportive and remain focused on verifiable facts, knowledge, and positive messages from credible medical resources unaccompanied by facts or data, as opposed to merely opinions.<sup>35</sup>

Dr. Saad Omer, at the Yale Institute for Global Health, offers his recommendations on how to navigate challenging vaccine hesitancy conversations. He recommends a version of the following:

1. Start with the fact that COVID-19 vaccines are **safe and effective**.
2. Connect your comments with **their values** (empathy: make sure that they feel heard).
3. **Don’t interrupt**. Try to understand them and “meet them where they are” instead. (Focus on empathy, not argumentation).
4. Help them feel **empowered** about arriving at their own final decision by addressing their fears about the disease. Their fears may be the primary obstacle.
5. Do not focus on the **myths and misinformation**. Those often have exploited existing fears and negative emotions that serve to reinforce vaccine hesitancy. It is folly to believe that once “the truth” has been shared, everyone will fall in line and get a vaccine.
6. Assume that **they are going to get vaccinated** (a strategy known as “presumptive communication”). “Let me know if I can take you to get your vaccination tomorrow.”

7. **Don't get discouraged.** Changing minds is often a long and difficult process. Giving up ideas based on paralyzing personal fears or strong emotions can take time, but your loved ones are worth it.

People have arrived at their vaccine hesitancy from many different starting points ranging from personal views and fears to the logistical problem of physically getting to a vaccination center during their operating hours. The overriding challenge, though, is recognizing that hesitating too long to be vaccinated gives COVID-19 more time to spread throughout the Black community, to say nothing of the new coronavirus variants.

### **Talking to Someone about Vaccine Hesitancy**

The sooner everyone gets vaccinated, the sooner we all will be protected, which means crafting effective conversations with members of the malleable middle. In the recent article “How to Talk to Someone about Vaccine Hesitancy,” the Cleveland Clinic recommends that the messenger:

- Aim for the **middle ground** (rather than a point at the far ends of the continuum). Communication is most effective when it is non-confrontational, non-judgmental, and involves no personal “put-downs” concerning one’s vaccine hesitancy. Blaming or belittling individuals for their fears is an unproductive endeavor.
- Try to understand **the other person’s doubts and fears** (which may be based on the lack of sound information they could use for final decision making). This may involve finding information sources that they trust. If they do not trust the Internet, avoid sending them a Facebook share. Instead, share an article written by a credible member of the medical profession.
- **Know your audience.**<sup>36</sup> Find out precisely *why* the person is hesitant to get the vaccine. It may be fear, politics, work schedules, etc., but you will need to know “where” and why they are stuck at this stage. Keep in mind that, even during highly intelligent conversations, emotions can overshadow objective reasoning. Everyone is not persuaded by science, according to Laura Huang, a professor of business administration at the Harvard Business School.<sup>37</sup> Empathy is just as important as information. Demeaning or insulting those who are fearful will never reduce their reasons for mistrust.

### **Conclusion**

Three years ago, the COVID-19 pandemic shook the country and the entire world. Suddenly, there were fears of massive body counts worldwide. At the time, there was no known cure, although there was no shortage of misinformation flooding the Internet.

Scientists around the world worked around the clock to develop a safe and effective vaccine. We all assumed that, once a vaccine was developed, tested, and released, there would be a run on hospitals and vaccination centers by millions of people demanding to be vaccinated immediately. It was unanticipated that a sizable portion of the population would be “vaccine hesitant” or “vaccine resistant” with a lifesaving remedy to coronavirus easily available to them.

In the African American community, COVID-19 illnesses, hospitalizations, and deaths were occurring at disproportionate rates compared to the size of America’s Black population.<sup>38</sup> African Americans were impacted more by the disease than any other racial group. However, a significant percentage of African Americans expressed serious doubts about vaccines being rushed into African American communities. While some degree of vaccine hesitancy was anticipated, the extent to which it occurred was unexpected. The so-called “Tuskegee experiments” became another factor contributing to Black vaccine hesitancy. Our long and troubled history with the American medical community resurfaced to haunt us in ways that made vaccine hesitancy more likely.

At this writing, vaccine hesitancy in Black communities has diminished some, but there are still significant numbers of African Americans in the North as well as the South who remain unvaccinated, posing a risk to everyone around them. It is our hope that the information contained in this handbook will be shared with as many members of the African American community as possible.

Being largely excluded from having access to adequate medical services was an unfortunate condition of the African American experience for centuries. Electing not to receive lifesaving medical treatment today, and exposing oneself and one's family to an agonizing and untimely death, is a most unreasonable and dangerous decision. When it comes to disease outcomes, hesitancy in being treated can be no different than a refusal to receive a lifesaving remedy. Either can be a death sentence to you and/or to your family. Act as if your life depends on getting the vaccine, because it does. Get vaccinated and be sure that all of your friends and loved ones are vaccinated as well. Everyone wins when everyone in our community has been vaccinated.

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# Vaccine Hesitancy:

## An Extremely Dangerous Decision



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This project was funded by the *"Vaccinate All 58"* Campaign of the California Department of Public Health