

# In Communities We Trust

## Institutional Failures and Sustained Solutions for Vaccine Hesitancy

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# About the Science, Technology, and Public Policy Program

The University of Michigan's [Science, Technology, and Public Policy \(STPP\) program](#) is a unique research, education, and policy engagement center concerned with cutting-edge questions that arise at the intersection of science, technology, policy, and society. Housed in the Ford School of Public Policy, STPP has a vibrant graduate

certificate program, postdoctoral fellowship program, public and policy engagement activities, and a lecture series that brings to campus experts in science and technology policy from around the world. Our affiliated faculty do research and influence policy on a variety of topics, from artificial intelligence to energy.

# Executive Summary

In winter 2020, a novel coronavirus (SARS-CoV-2) that caused COVID-19 started its spread across the globe, and by July 2020, over 500,000 people worldwide had died of the disease. By March 2021, there were over 120 million cases and over 2.8 million deaths. To combat the pandemic and return to “normalcy”, experts estimate that at least 80% of the world’s population needs to be resistant to the virus, and most of the world’s population will require vaccination. This will be a challenge. In addition to facilitating widespread distribution, governments will need to combat “vaccine hesitancy”: an individual’s reluctance to get vaccinated or vaccinate their children. In the United States, 71% of the adult population says it is willing to get vaccinated, and the numbers are much lower in Europe (Ipsos & World Economic Forum, 2020; Summers, 2021).

Contrary to popular belief, not all vaccine hesitancy is the same. Nor is it simply the result of ignorance or antipathy towards science. At its root, vaccine hesitancy is about institutional mistrust. Communities question whether their governments, and scientific, technological, and medical institutions, really represent their needs and priorities. Long legacies of mistreatment of marginalized communities further fuels this mistrust.

In this report, we examine analogical case studies that help us understand the roots of institutional distrust and ultimately, vaccine hesitancy. This method allows us to systematically analyze previous examples of the relationships between science, technology, policy, and society to understand the consequences and challenges of new technology. Our analysis identifies sources of public mistrust and anticipates better approaches for establishing community trust, especially for those from marginalized or disadvantaged backgrounds. We reveal two main causes of public mistrust:

1. limitations and failures in scientific and technical institutions, and
2. institutionalized mistreatment of marginalized communities.

Both, we argue, ultimately help to legitimate the circulation of false information and sow vaccine hesitancy.

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*Not all vaccine hesitancy is the same. Nor is it simply the result of ignorance or antipathy towards science.*

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On the basis of this analysis, we provide recommendations to help restore public trust,

and use additional model cases to describe how they might be implemented.

## Limitations and Failures in Scientific and Technical Institutions

In recent years, high-profile technological disasters have illustrated multiple limitations and challenges related to science and technology policy institutions. Sometimes the problem is a cozy relationship between industry and government, such as in the United States Food and Drug Administration's approval of Vioxx. Additionally, bureaucratic culture is often structured to minimize problems, which has led to disasters such as the space shuttle Challenger explosion.

Second, science and technology policy institutions tend to base their decisions on systematic—and often quantitative—evaluation of scientific data by technical experts. But this often excludes community knowledge and expertise. Drawing on disastrous examples such as the Flint water crisis, we show how these limitations can produce catastrophic results. But even more relevant to vaccine hesitancy, these approaches alienate people who are then less likely to trust expert institutions in the future.

Finally, there are visible weaknesses in both how scientists and scientific institutions police themselves and how they communicate uncertainties. Across multiple disciplines, scientists struggle to reproduce the results of other studies. This causes not only their peers, but also lay people, to question both

scientific methods and findings. In addition, there is more scrutiny (known as “post-normal science”) for scientists working on controversial issues. Under these conditions, they often struggle to communicate the uncertainties and limitations of their findings, which can also foment increased distrust.

## Institutional Mistreatment of Marginalized Communities

Both governments and science, technology, and medical institutions have long legacies of mistreating marginalized communities, including historically disadvantaged communities of color. As a result, these communities feel alienated and are now skeptical about the flurry of attention to vaccinating them. In fact, they may even see vaccine refusal as a form of resistance.



*Doctor drawing blood from a patient as part of the Tuskegee Syphilis Study, 1932. (Credit: National Archives, CC-0)*

Structural racism has played a pernicious role in public health and medical care for centuries. This includes a long legacy of devaluing the medical concerns of people of color. For example, as early as the 18th century, physicians, scientists, and medical institutions in the United States believed that Black people were less susceptible to infectious and other diseases. Legalized segregation and racism also prevented Black patients from obtaining access to adequate health care at better-resourced white medical institutions. People of color have been used as experimental subjects without proper consent or remuneration. But members of marginalized groups do not need to look to history to find reasons to distrust the medical establishment. In the United States today, Black, American Indian, and Alaska Native women are two to three times more likely to die from pregnancy-related causes than white women, despite the fact that most pregnancy-related deaths are preventable (Centers for Disease Control and Prevention, 2019).

Furthermore, the scientific legacy of eugenics in Western nations has created ongoing mistrust among both communities of color and the disabled. In the early 20th century, thirty-three US states enacted forced sterilization laws, which took away reproductive freedoms from women and men of color, the incarcerated population, and those labeled as “mentally disabled” or “feeble-minded”. Even though these laws have largely been rescinded, some argue that eugenic ideals are embedded in current public health and social welfare policies.

Our analogical cases also show that government and public health institutions have long legacies of coercing citizens to participate in initiatives that are designed to contribute to the public good, but these disproportionately hurt marginalized communities. For example, some poverty alleviation programs such as welfare and food stamps include onerous requirements and systems of surveillance meant to control recipients’ behaviors. Vaccine hesitancy may become a place of resistance for these communities who feel that they have been controlled and that their needs and perspectives have been ignored for decades.

## False Information: A Consequence of Institutional Failures

Along with the institutional failures described above, governments also erode citizen trust when trying to limit and shape publicly available information to maintain their power and legitimacy. When citizens feel they cannot trust leaders and institutions, they rely on those they feel they can trust: themselves, their friends and family, and media outlets that seem to share their perspectives and concerns. This can become a breeding ground for false information. Audiences now have more choices for news sources, and many of these outlets cater to specific demographics that confirm their preconceived beliefs. This in turn makes skeptical publics even more hesitant to believe in governments they distrust. False information has an especially high cost for public health and vaccine hesitancy in particular.

## Recommendations

Overall, institutional failures in science, medicine, public health, and government cultivate mistrust among members of the public and are likely to result in vaccine hesitancy. Repairing this institutional trust cannot be solely addressed in the short term; it requires sustained solutions, and our recommendations reflect that need. We suggest interventions focused on building community trust, increasing research and educational funding, and improving accountability and oversight within institutions.



### Building community trust

#### RECOMMENDATIONS

Public health officials need to develop vaccination initiatives in partnership with local institutions and leaders, particularly to serve marginalized communities. Scientific, policy, and public health institutions should also work with these publics to develop long-term trust while national governments should fund local-level public engagements. Key to all of these processes is listening to people's priorities and concerns and incorporating these insights into sustained interventions.

1

In the short term, public health officials should develop vaccination initiatives in partnership with local institutions (e.g., schools, houses of worship, community centers, sports leagues) that community members already trust. Information should be culturally relevant and appropriate (and in multiple languages as appropriate), described simply, and in formats that are accessible to people with disabilities.





2

Proactively ensure that vaccination sites are located in marginalized communities (especially because these communities are often at the highest risk of adverse outcomes).

3

Scientific, policy, and public health institutions must develop community trust for the longer term. To do this, they must build ongoing partnerships with communities and their leaders to create deep relationships and facilitate a two-way flow of knowledge. Public engagement efforts should be designed to listen to community needs and concerns rather than “educate,” with the recognition that publics have expertise. Let people ask questions and give honest responses, which can enable more active participation and allow people to ask for what they want to see in vaccine distribution and development.

4

At all levels, from leaders to the lab, encourage and facilitate honest communication about scientific limitations and uncertainties. Communicate clearly about the processes of vaccine review and approval and ensure that community knowledge and expertise are integrated into these processes. Commit to transparency about the risks of the vaccine and acknowledge the unknown.

5

National governments should fund local-level public engagement (rather than national education campaigns).

6

Local and state governments should create regular deliberative forums (virtual or in-person) to incorporate community perspectives (particularly those from historically marginalized communities) into day-to-day policymaking. This will help to simultaneously improve decision making and establish closer relationships and trust in the long term.



## Research and educational funding

### RECOMMENDATIONS

National governments must provide more funding for research that engages and responds to community priorities including health disparities. They should also support more social science research on the social dimensions of science, technology, public health, and medicine, and ensure that findings are integrated into public health practice and policy, including vaccine initiatives. In addition, there should be greater support for programs designed to enable marginalized communities to excel in STEM fields.

7

Provide additional research funding for and enable community-driven research to investigate community public health and medical priorities, and ensure that the research insights developed inform public health practice and policy.

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Fund training and support programs to enable people from marginalized communities to become doctors, scientists, and public health officials, and fund evidence-based efforts to make those fields more open to these communities.

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9

Create a national initiative focused on health disparities and health research that centers the lives, bodies, and experiences of historically disadvantaged communities of color and addresses disincentives to doing this type of research. This should include both biomedical and social science research into, for example, structural inequalities in healthcare. This research should then inform public health practice and policy.

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10

Fund social science research dedicated to understanding past institutional failures and preventing future institutional failures, and use this to inform organizational and bureaucratic culture and practices.



## Accountability and oversight

### RECOMMENDATIONS

Science and technology policy institutions must ensure that their processes are accurate, fully transparent, and reflect community knowledge and needs.

11

Create effective accountability structures at the national and state level for people who perpetrate bias in medicine, alongside an effective grievance structure for people who experience bias in medicine. This would include a clear and public accountability process for failures.

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12

Ensure that vaccine regulatory processes are transparent and that citizens have the opportunity to participate. They should be included on vaccine advisory committees.

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13

Governments (ideally at the national level) should require physicians to report adverse events linked to vaccines, and fund and create processes for better data collection of adverse events.

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14

Scientific and science policy institutions (e.g., research funding agencies, universities) should increase participation of marginalized communities in oversight committees, including reviews of ethical and scientific aspects of study protocols.

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15

Provide regulatory oversight for social media and news outlets to reduce misinformation and disinformation.

# Introduction

## KEY TAKEAWAYS

- As of May 2021, the COVID-19 pandemic has killed over 3.2 million people globally and sickened over 155 million.
- Governments and international organizations have set a goal of worldwide vaccination at levels high enough to achieve herd immunity and stop the spread of the virus.
- Vaccine hesitancy—an individual's reluctance to get vaccinated or vaccinate their children—is a barrier to successful immunization campaigns.
- Analogical cases across science and technology sectors can provide crucial insights on how to implement vaccination campaigns successfully.

In the Spring of 2020, the world turned upside down when a novel coronavirus (SARS-CoV-2), which causes the disease COVID-19, began to spread. Originally detected in Wuhan, China, it quickly made its way to South Korea, Italy, and Iran, and then around the globe. On March 11, the World Health Organization (WHO) declared COVID-19 a pandemic and by July 2020, 500,000 people had died of the disease worldwide. The numbers would increase in part because the disease transmitted easily through the air even by asymptomatic people. Symptoms include cough, fever, loss of taste and smell, and shortness of breath. About 15% of sufferers become seriously ill, and case fatality varies by country, ranging from 1% to over 8% (Johns Hopkins University, 2021).

Although scientists and physicians have been developing better treatments, worldwide vaccination at levels high enough to achieve herd immunity is the ultimate goal (Centers for Disease Control and Prevention, 2021). Herd immunity occurs when enough people in a population are protected from getting a disease, either through vaccination or prior infection, that it becomes difficult or impossible for the disease to spread. The percentage of protected people needed to achieve herd immunity varies by disease, and experts estimate that at least 70% of the population needs to be protected from COVID-19 to reach herd immunity. To reach this goal, governments have made significant investments in vaccine development and procurement. The German government provided Pfizer and BioNTech with \$445 million to develop its vaccine, while the

Canadian government provided two of its companies, AbCellera and Medicago, with \$150 million to develop vaccine candidates (Griffin & Armstrong, 2020; Abedi, 2020). India's government has spent over \$13 million on the development of Covaxin and other vaccine candidates (Dutt, 2020). The United States government directed more than \$10 billion for vaccine development among major pharmaceutical companies, including Johnson & Johnson, Moderna, AstraZeneca/ University of Oxford, Novavax, Pfizer, and Sanofi/ GlaxoSmithKline both through direct grants and promises of procurement (Baker & Koons, 2020; Barone, 2020).

After clearing the hurdles of developing, manufacturing, and distributing COVID-19 vaccines, the final challenge is administering the vaccines quickly, safely, and equitably. Of the many barriers to achieving levels of vaccination required for herd immunity, there has been great concern about vaccine hesitancy (CBS News, 2021; Henry, 2021; Lazarus et al., 2020). Governments, public health officials, and media outlets have called attention to people's propensity to believe false information and distrust scientific expertise (Henry, 2021). While some of these factors may be at play, it is difficult to convince those who have deeply held beliefs

(Hall & Raimi, 2018) or who are making decisions based on their own needs and individualized risk assessment (Reich, 2018). Nevertheless, the root of these beliefs is invariably institutional mistrust (Goldenberg, 2021). Therefore, this report focuses on the

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institutional failures—in science, medicine, public health, and policy more generally—that have produced community mistrust, and offers recommendations for what local, state, and national governments can do about it.

## Vaccinating the World

As of March 2021, a total of 263 COVID-19 vaccines are currently in development (World Health Organization, 2021), with 81 in clinical trials and at least 182 preclinical vaccines under investigation in animals (Zimmer et al., 2020). Drug regulators around the

world have approved a handful, although availability varies. In December 2020, the United Kingdom authorized the Oxford–AstraZeneca vaccine and the United States approved the Pfizer–BioNTech and Moderna vaccines (Austen, 2020; Mueller, 2020). Immunizations began soon afterward and the two countries have approved more vaccines in recent months. China, Russia, and India have also developed vaccines and plan to distribute them widely among low and middle-income countries (Cohen, 2020; Cyranoski, 2020; Tan, 2020).



Credit: UNICEF

## Vaccine Technology

There are three major types of COVID-19 vaccines. The first, used for the Johnson & Johnson and AstraZeneca vaccines, involves virus vectors. This is a traditional approach, which has previously been used for the smallpox vaccine among others. These vaccines introduce weakened viruses

into the body to infect cells and trigger an immune response. A single dose can produce a prolonged immune response. However, they also require the growth of large quantities of the virus, under optimal biosafety conditions, which can be difficult to scale up (van Riel & de Wit, 2020). The second type of COVID-19 vaccine, developed by Sinovac Biotech in China, uses inactivated virus. This method treats viruses with heat, chemicals, or radiation so they cannot replicate, but can still trigger an immune response. Hepatitis, polio, and some types of flu vaccines also use this technology (Aditya & Lyu, 2020). It is generally very safe and can even be used on people with weaker immune systems. However, inactivated viruses often trigger lower immune response rates, which means that multiple doses might be required for the vaccine to be effective.

Moderna and Pfizer–BioNTech’s COVID vaccines, approved in the United States, Canada, and many other countries, employ messenger RNA (mRNA) technology. These vaccines are made up of synthetic fragments of the virus’s mRNA. A body’s cells read the mRNA sequence and produce SARS–CoV–2’s spike proteins, which then enables the body to develop an immune response (Malcom, 2020). Because it only involves gene sequencing, mRNA vaccines are relatively quick and inexpensive to develop. RNA can be produced in laboratory settings from DNA sequence templates, which eliminates the need for mammalian cells required for conventional vaccines. It is also safer because patients are not exposed to potentially infectious elements of the virus. Because production is lab-based, it is also easier to standardize and scale-up.

However, there are also many challenges associated with mRNA vaccines. Because COVID-19 is the first disease for which these vaccines have been approved for human use, the regulatory hurdles have been higher. Perhaps the biggest challenge is that they need to be shipped and stored at  $-70^{\circ}\text{C}$  (Pfizer, 2020) to protect the mRNA (Corum & Zimmer, 2020). Each shipment of doses requires 23 kg of dry ice which needs to be replenished within 24 hours upon delivery and 5 days after arrival. The vaccine must be thawed before injection and diluted with saline (Corum & Zimmer, 2020). After dilution, vaccines must be used within 6 hours. Since the smallest possible order is 975 doses, any deviation from the standard operating procedure can result in an enormous waste of limited doses, which is especially challenging for rural hospitals and nursing homes where there might not be enough people to use vaccines before they expire (Branswell & Silverman, 2020).

## Vaccine Distribution

Ensuring that COVID-19 vaccine supply meets demand is a serious challenge, especially because there is great urgency to vaccinating populations so that societies and economies can recover. Previous vaccination campaigns (e.g. smallpox, polio) have taken decades. But in today's globalized world, rapid vaccination is crucial; otherwise, scientists may need new vaccines to manage an ever-mutating virus. The challenges of vaccine distribution depend on a country's political structure, health care system, and vaccine supply chain requirements. In countries with national health care systems, the

campaign's administration is top-down. In China, where 97% of its population uses public health insurance (Guo, 2017), the national government has greater control over distribution to "key priority groups" such as hospital workers. However, there is more variation at the local level, with individual provinces purchasing and charging residents for doses. This may make vaccination more challenging for the rural poor who might not be able to afford \$35/dose (Wee, 2020). In the United Kingdom, which has the National Health Service (NHS), a national independent committee of academics and medical experts has determined vaccine priority for citizens. In phase one, they divided the priority population into nine groups and determined vaccination by age and vulnerability (Guo & Jee, 2020). More than 50 centralized NHS hubs are coordinating vaccine distribution to areas most affected by the virus (Warren & Pogkas, 2020).

By contrast, the US approach is much more decentralized. While the national government has provided guidance from the Center for Disease Control and Prevention's (CDC) Interim Playbook for COVID-19 (Guo & Jee, 2020), US states are responsible for creating their own vaccine distribution plans which have led to massive differences in strategy (The Council of State Governments, 2021). The US healthcare system is a complex hybrid between publicly and privately funded systems and programs. The majority of the population is covered by private insurance plans through their employers while vulnerable populations such as lower-income people and the elderly receive their health care through government-supported



programs (Tunstall, 2018). Additionally, there is no clear national register of who might be a priority for vaccination. This means that states make their own choices about who to prioritize, but they also lack a centralized mechanism to identify eligible people in their own jurisdictions because state and county health departments do not have access to medical records.

States may also change distribution strategies at any time. For example, after vaccinating frontline healthcare workers for the first four weeks, Florida's governor Ron DeSantis signed an executive order to vaccinate all seniors 65 and older instead of prioritizing essential workers as the CDC guidelines had recommended (Flores & Royal, 2021). This created overwhelming demand as thousands of seniors across the state unsuccessfully waited in long lines, slept overnight in cars, circumvented jammed phone lines, and crashed websites to set up appointments (Mazzei et al., 2021). Finally, although Operation Warp Speed was supposed to help with both vaccine development and distribution (e.g., ensuring manufacture of vials and syringes, rapid, nationwide coverage), supply problems plagued the initial US vaccine rollout. President Biden has now invoked the Defense Production Act to minimize these challenges (United States Department of Defense, 2020; Schumaker, 2021).

## Understanding COVID Vaccine Hesitancy

Though it is not known exactly how many people need to receive the vaccine in order to achieve herd immunity, experts estimate that it is at least 70% (McNeil Jr., 2020). However, there is great concern that many people will refuse vaccination. In December 2020, only 71% of US adults surveyed claimed that they would be willing to take the vaccine, which is less than the threshold the total population must meet (Hamel, et al., 2020). This resistance could seriously hamper efforts to halt the pandemic. But not all vaccine hesitancy is the same, nor is it simply the result of ignorance or antipathy towards science (Goldenberg, 2021). Rather, as we discuss throughout this report, it is often quite rational: rooted in institutional distrust or individualized risk calculations.

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*An effective campaign to overcome COVID-19 vaccine hesitancy... must carefully and respectfully consider the wide range of circumstances that underpin that hesitancy.*

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Therefore, an effective campaign to overcome COVID-19 vaccine hesitancy must be based on an understanding of the many reasons people and communities may resist the vaccine, and



must carefully and respectfully consider the wide range of circumstances that underpin that resistance. Perhaps most importantly, our research shows that in order to address the institutional mistrust that produces vaccine hesitancy, we cannot simply develop better communication strategies or fund educational campaigns. Scientific, public health, medical, and government institutions must develop long-term, systemic solutions, which we identify in our Recommendations section.

## Defining “Institutions”

Throughout this report, we use the word “institution” to refer to both formal organizations such as government agencies and pharmaceutical companies, as well as informal social organizations such as the peer review system.

Many people are vaccine hesitant due to *mistrust of scientific institutions and processes*. As noted above, many vaccine skeptics do not reject the science of the vaccines but question the trustworthiness of scientific governance meant to ensure vaccines’ safety (Goldenberg, 2017). In an international survey conducted before COVID-19 reached pandemic status, the majority of surveyed people said they had at least some trust in scientists to do what is right for the public, but sizeable

minorities expressed skepticism about specific scientific and technical advances, including the safety and efficacy of childhood vaccines (Funk et al., 2020). These attitudes varied by country and political orientation. France has had increasingly high levels of vaccine hesitancy over the last 30 years due to factors that include the public controversy surrounding a vaccination campaign related to the 2009 H1N1 pandemic, the deterioration of the relationship between public health authorities and the medical profession, the public distrust of the government, and an ongoing funding crisis for public hospitals (Ward et al., 2019). Similarly in the United States, a study found that people who generally had less trust in government were also more likely to be vaccine hesitant (Callaghan, et al., 2021). Mistrust also arises from previous institutional failures, such as the CDC and WHO’s incorrect advice early in the pandemic that masks were unnecessary (Oreskes, 2020).

Scientific, medical, and public health institutions also have a long history of *mistreating marginalized communities* that extends to the present day. In the context of the COVID-19 pandemic in the United States, Black, Latinx, and indigenous populations have been dying of COVID-19 at rates far higher than white Americans (Egbert et al., 2020), due to both structural inequalities on a societal level, and disparate treatment at the individual level (Bajaj & Stanford, 2021). There have been numerous reports of Black people dying after hospitals dismissed or ignored their symptoms: a doctor who posted a video about her experience of being treated “like a drug addict” (Eligon, 2020), a 5-year old girl who was one of the first children

to die of COVID-19 (Barmore, 2020), and a father and son who died within hours of each other in Detroit (Harper, 2020). Given these experiences, it is no surprise that the odds of COVID-19 vaccine refusal are significantly higher for Black people than almost all other groups in the study population (Callaghan, et al., 2020).



*Credit: Tyler Russell / Connecticut Public Radio*

The mistrust cultivated by these institutions leaves the public vulnerable to false information and conspiracy theories. There is longstanding evidence that misinformation about childhood vaccines, such as false claims that they cause autism, or that they are part of a government plot, spurred vaccine refusals at rates high enough to undermine herd immunity for previously eradicated diseases like measles and whooping cough (Leach & Fairhead, 2007). Anti-vaccine organizations spread misinformation intentionally, such as one group that targets Black Americans with misinformation about vaccine safety. This group builds its discourse on existing

mistrust of the government due to the long history of institutionalized mistreatment described briefly above (Callaghan, et al., 2021). Misinformation about vaccines can also spread more organically. In one school community where some parents were vaccine hesitant, new parents who had previously vaccinated their children on schedule began refusing vaccines after speaking with these vaccine-hesitant parents (Sobo, 2015). These misinformation campaigns often gain power because they capitalize on histories of government failure, corruption, and overreach.

## Our Analytical Approach: Analogical Case Studies

We adopt an analogical case comparison approach to understand potential hesitancy toward the COVID-19 vaccine and how to address it. By analogical case comparison, we mean systematically analyzing previous examples of the relationships between science, technology, policy, and society to understand how new technology might emerge and the challenges it will pose.

Policymakers often argue that they cannot anticipate the implications of emerging science and technology because innovation moves so quickly and its consequences are unpredictable. But humanists and social scientists who study these topics, from science and technology studies (STS) scholars to historians, teach us that the consequences of innovation are more predictable than we think, and therefore many of their moral, social, economic, environmental, and public

health challenges can be anticipated early and addressed in the development process and/or through public policy (Stilgoe et al., 2013). Methods of “anticipatory governance” include scenario-planning and other stakeholder engagement exercises (Kuzma et al., 2016; Selin, 2011), initiatives to help scientists and engineers reflect on the ethical, social, and environmental consequences of their choices as they work in the laboratory (Fisher et al., 2006), and deliberative democratic efforts that value lay insights about the world and community experiences with technology (Hamlett et al., 2013; Stirling, 2008).

These scholars offer two important lessons for analyzing the relationships between science, technology, policy, and society. First, science, technology, and their consequences tend to reflect the social and political contexts in which they are developed. The privatized and competitive health care market in the United States, for example, tends to favor commodifiable technical solutions for disease rather than less lucrative preventive approaches or changes to the built environment. Second, responses to previous interventions offer insights into the kinds of concerns and resistance that might arise, groups who might be affected, and solutions that might be feasible with emerging innovation. For example, limiting government surveillance and maintaining individual privacy has long been a priority for citizens, especially in the Western world. It is therefore unsurprising that contact tracing efforts for COVID-19—whether human or technological—have been largely unsuccessful (Martonik, 2021).

Building on these insights, the University of Michigan’s Technology Assessment Project (TAP) is developing a process to use analogical case comparison to enhance our understanding and governance of emerging science and technology. Guston and Sarewitz (2002) argue: “Studying past examples of transformational innovations can help to develop analogies and frameworks for understanding and anticipating societal responses to new innovations.” This analogical case comparison approach joins a suite of methods designed to anticipate the consequences of emerging science and technology in order to better govern them.

We first used the analogical case study approach to analyze the implications of using facial recognition technologies in schools (Galligan et al., 2020). A variety of cases, from predictive policing to biobanks, helped us identify five implications: we argued that the technology would exacerbate racism, normalize surveillance, limit the definition of acceptable students, create new commodities and markets, and institutionalize algorithmic inaccuracies. It is important to note here that we define analogical technologies broadly, to include interventions that have technical, human, and physical components (what scholars refer to as “sociotechnical systems” (Bijker, Hughes, & Pinch, 1987; Mackenzie and Wajcman, 1985). In the months since we published that report, we have already seen our predictions come true as schools and universities have relied more heavily on biometric technology during the increase in virtual schooling triggered by the pandemic (Barber, 2020).

For our previous report, we investigated cases analogical to facial recognition, an emerging technology. But in this report, we focus on analogical cases to the institutional mistrust that produces vaccine hesitancy. Guston and Sarewitz (2002) note: “by assessing the variety of strategies and tactics used to manage conflict over, and allocate benefits of, the impacts of new science and technology, case-based approaches can help to conceptualize more effective approaches for the future.” Reading both scholarly literature and primary sources, we looked at previous infectious disease outbreaks and vaccination campaigns, to understand the issues that arose, how they were resolved, and what they might tell us about responses to COVID-19 vaccines. There, we began to see coercive tactics by governments and public health workers, mistreatment of already marginalized communities, and growing citizen distrust in science, technology, medicine, and public health institutions. This inspired us to investigate other examples of these kinds of scientific and institutional failures, and the responses to them, from the history of eugenics to the Flint

water crisis. We sought, in other words, to investigate analogical cases that would help us understand both the roots and shape of institutional mistrust to understand both how it might appear in the case of COVID-19 and how it might be resolved.

We also took an additional step that we had not in our facial recognition study. In addition to the analogical cases that helped us understand the history of mistrust in scientific, technological, medical, and public health institutions, we identified model cases that can serve as examples for how to repair and strengthen community trust. These cases also vary widely, from the Manhattan Project to the Healthy Flint Research Coordinating Center. We list both analogical and model cases below, which each link to their discussion in the text.

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*We identified model cases that can serve as examples for how to repair and strengthen community trust.*

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## Analogical Cases to Vaccine Hesitancy

[Click case names for detail](#)

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1793 yellow fever epidemic →

1915 British and Australian propaganda against Germans →

19th century England contact tracing →

Air quality impacts of Shell chemical plant in Norco, Louisiana →

Boeing 787 MAX →

Coal mining effects in Western United States and Central Appalachia →

Coerced sterilization →

Climate change post-normal science →

Eugenics in the United States →

Flint water crisis →

Henrietta Lacks →

HIV beliefs among some Black communities in the United States and South Africa →

Honey bee colony collapse disorder →

NASA Challenger shuttle →

Operation Talon →

Pakistani vaccination campaign as US alibi to find Bin Laden →

Papillomavirus Vaccine (VPH) and misinformation in Colombia →

Pulse oximeter →

Sheep contamination post Chernobyl nuclear disaster →

Smallpox Eradication Program in India and Bangladesh →

Spirometer →

Thalidomide →

Tuskegee syphilis study →

Vioxx →

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## Model Cases for Strengthening Community Trust

[Click case names for detail](#)

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Association of Black Women Physicians →

Ask Away →

CACHÉ →

Centre for Aboriginal Medical and Dental Health (CAMDH) at the University of Western Australia →

Colombia's 2018 Census planning →

Complete Count Committee Programs →

Drug Commission of the German Medical Association →

European Medicines Agency →

Fairness Doctrine →

The Healing of the Canoe Project →

Healthy Flint Research Coordinating Center →

Human Genome Project →

Los Angeles County Community Health Improvement Collaborative →

Manhattan Project →

Mississippi Renewal Forum →

National Medical Association COVID-19 task force →

NOLA Ready system →

North Carolina's Latinx population soccer teams →

Patients' Tumor Bank of Hope →

Patient-Centered Outcomes Research Institute Peer Review Program →

The Philadelphia Black Doctors COVID-19 Consortium →

US National Science Foundation funding →

US Title IX of the Education Amendments of 1972 →

vTaiwan →

The Wales Cancer Bank →

# Limitations and Failures in Scientific and Technical Institutions

## KEY TAKEAWAYS

- Poor communication about scientific limitations and uncertainties, coupled with public awareness of scientific failures, creates public mistrust over the accuracy and relevance of scientific recommendations.
- Communities are frustrated that their knowledge and expertise are not taken seriously in science and technology policymaking.
- Failure to regulate technologies has produced multiple high-profile disasters, and fostered skepticism of government oversight.

In theory, publics accept scientific facts because they have been produced using standard, replicable methods and their results are reviewed by their peers before they are published. Similarly, science and technology policy institutions—whether the Centers for Disease Control in the United States or the United Kingdom’s Medicines and Healthcare products Regulatory Agency—maintain their legitimacy because their decisions are based on the recommendations of technical experts who are well-versed in the relevant

scientific knowledge and because there are regulations in place to minimize bias.

But in recent decades, trust in both policy institutions and science itself has been eroding. According to the Organization for Economic Cooperation and Development, public trust in government is low and on the

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*Widespread distrust is particularly problematic during a pandemic.*

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decline around the world (Organization for Economic Cooperation and Development, 2019). Even in normal circumstances, public trust is important for sustaining the legitimacy of public institutions and maintaining social cohesion. Widespread distrust is particularly problematic during a pandemic, when communities must rely on their governments for disease mitigation and containment as well as vaccine development and distribution. Even though public trust in science and scientists is generally very high, there is some divergence in the United States depending on political party affiliation (Funk et al., 2020). Trust drops when communities are asked about specific technical interventions. This makes sense: as science and technology have become more ubiquitous in our lives, from our reliance on prescription drugs to digital technologies that help us connect to the world, communities have become more aware of their specific limitations and uncertainties, and the consequences of failure.

Lay people are also becoming more aware of and hurt by limitations and failures in regulating technologies. Sometimes, the problem is one of regulatory capture by industry. But the problems can also be organizational and cultural, as with the “normalization of deviance” within NASA (National Aeronautics and Space Administration) that led to the Challenger and Columbia space shuttle disasters. We also see a growing distance between community needs and experts’ knowledge on decision making. Communities are increasingly challenging quantitative, supposedly generalizable standards that have traditionally been viewed as ideal and legitimate because they do not

reflect their lived experience or represent their needs.

## Excluding Community Expertise from Policy Making

Science and technology policy institutions tend to base their decisions on systematic evaluation of scientific data by technical experts. In recent decades, these institutions have incorporated multiple procedures to win public trust, including improved transparency about their procedures, public notice and comment periods, and conducting impact evaluations. Despite these changes, the practices and policies of the institutions still privilege technical expertise at the expense of regular people. As a result, the needs and knowledge of marginalized communities often go unheard.

This is problematic for a few reasons. First, science and technology policy institutions lack crucial knowledge and expertise relevant to their decision making. Those without technical expertise and knowledge often have crucial expertise rooted in their lived experiences. Second, because lay knowledge and expertise are rarely incorporated into science and technology decision making, individuals feel alienated and are less likely to trust these expert institutions. Third, because of the lack of diversity in terms of race, ethnicity, gender, socioeconomic status, and disability among technical expert communities, it means that decision making is likely to represent the needs and perspectives of dominant, privileged groups.

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*Because lay knowledge and expertise are rarely incorporated into science and technology decision making, individuals feel alienated and are less likely to trust these expert institutions.*

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In the case of COVID-19 vaccines, we see this playing out in vaccine distribution, where access to the vaccine is highly inequitable even despite some attempts to reach vulnerable populations first, and vaccine hesitancy is sometimes higher in those same populations due to longstanding feelings of alienation (Cobb, 2020).

One iconic example of this phenomenon comes from the United Kingdom's response to radioactive fallout from the Chernobyl nuclear disaster in 1986 (Wynne, 1992). Radioactive fallout contaminated sheep flocks and upland pastures in Cumbria in northern England, but scientists and political leaders initially dismissed these effects as negligible. Six weeks later, the government placed a ban on the migration and slaughter of sheep from the 1,670 county farms in the area. Scientists assured the farmers that the ban would only last three weeks because the radioactivity would eventually fall to safe levels. However, three weeks later, the government announced an indefinite extension of the ban. Scientists advised farmers, who were conflicted about whether to sell the contaminated sheep or to wait out the ban, to wait because they believed that the contamination levels would eventually drop. Given their knowledge

of grazing practices, farmers suspected that the problem was that the sheep were eating contaminated grass. Still, the scientists insisted that the radiation levels would eventually fall. They did not, and the farmers ended up with costly complications in

their farm management cycles and serious disruption to their income, which could have been avoided had scientists initially incorporated the farmers' lay knowledge and expertise.

Honey bee colony collapse disorder (CCD) provides a similar and more recent case. Long-time commercial beekeepers in the United States argue that newer agricultural insecticides are the main factor responsible for CCD (Suryanarayanan & Kleinman, 2013). However, both the US Environmental Protection Agency (EPA) and scientists have rejected these claims, citing the lack of experimental evidence by academic and industrial toxicologists. However, many of these toxicological experiments were conducted in labs under ideal conditions without considering the effects of mixing chemicals together, a problem that beekeepers have repeatedly raised. Additionally, scientists only measured the lethal effects of specific chemicals and did not consider the possible environmental effects of low or "sub-lethal" levels of insecticide (Kleinman & Suryanarayanan, 2013). The EPA's decision as a result of focusing on statistically significant effects and laboratory



studies, dismissed the experiential expertise and precautionary approach of experienced beekeepers.

We see even greater disregard for lay knowledge and expertise in the case of the Flint water crisis (Pauli, 2019). Due to financial insolvency, in 2014 the city of Flint switched its water source from Lake Huron to the Flint River (Sobeck et al., 2020; Cuthbertson et al., 2016; Morckel & Terzano, 2019). Despite knowing that Flint River water was more acidic, the Michigan Department of Environmental Quality did not require that the water be treated with corrosion-control chemicals (Morckel & Terzano, 2019). Flint leaders followed suit, arguing that they could not afford additional water treatment costs (Sobeck et al., 2020). For months local

Their findings were based on their daily experience rather than quantitative data, and they were dismissed as ignorant (Pauli, 2019). It took the involvement of scientific and medical specialists for their concerns to be taken seriously. Residents were dismissed again when they suggested that the Flint River water had caused an outbreak of Legionnaires Disease until a separate set of scientific experts validated these concerns as well (Zahran et al., 2018). By the time the government finally acted, first providing “point-of-use” filters and then replacing some of the pipes, the trust of residents had eroded completely. Despite the claims of the local and state government and scientific experts, residents still worry that structural issues related to the water system have not been resolved (Yang & Wellford, 2019). There is a significant concern that the Flint water crisis will cause developmental issues for children in the generations to come (Green, 2019).

Even when regulatory institutions try to take public concerns into account, we see how structurally difficult it is to do so. In the 1990s for example, Black residents of Norco, Louisiana worried about the impacts of the local Shell chemical plant on air quality (Ottinger, 2010). Louisiana air quality standards specified the maximum concentration of air contaminants for either an eight-hour or an annual average. This approach assumed that the major risk was long-term exposure to hazardous chemicals. The Norco residents worried about the health impacts of high short-term exposure due to flares, accidents, and other unplanned releases. They developed a bucket monitoring system, which would collect air at moments



*Water samples from Flint and Detroit, 2015. (Flint Water Study)*

citizens alerted scientific experts at the Environmental Protection Agency (EPA) and Michigan Department of Environmental Quality about problems with the water.

when they worried they were most at risk, such as when they noticed a particularly bad smell. EPA officials questioned the validity of the data, acknowledging that while it might provide some indication of a problem, they were reluctant to treat it as evidence in its own right. Today, communities in the vicinity of chemical plants around the world have adopted the bucket collection method, but regulators remain resistant.

Finally, efforts to improve the welfare of the overall population can often end up hurting the most marginalized communities, creating an “equity deficit” (Bell, 2017). For example, amendments to the Clean Air Act in 1990 required stricter emission standards, but also provided companies more flexibility in how they reached those standards. As a result, many coal plants switched to low-sulfur coal, primarily found in the Western United States (Wyoming, Colorado, and Montana) and Central Appalachia (West Virginia, eastern Kentucky, and southwest Virginia). This shift expanded the practice of mountaintop removal for mining, which destroyed over 1 million acres of land, over 500 mountains, and buried 2,000 miles of streams and sources of freshwater in West Virginia. It created a major public health crisis and accounted for 1,200 additional deaths per year for people living in impoverished communities where low-sulfur coal mining resulted in poor water and air quality. Similarly, while the use of solar photovoltaic (PV) panels will reduce carbon emissions, their production can be hazardous and produce massive volumes of electronic waste (Mulvaney, 2019). China is experiencing widespread land and water pollution because it has increased production of solar panels

under lax environmental and worker safety regulations (Cha, 2008).

## Government Failure in Regulating Technologies

At the same time that policymakers and their technical experts struggle to incorporate lay and experiential expertise into their decision making, their decisions have also produced high-profile and consequential failures in regulating new technologies. This also contributes to public mistrust. Consider the case of thalidomide. In the late 1950s and early 1960s, 46 countries approved it for use in insomnia, tension, and morning sickness during early stages of pregnancy before there was clear evidence to confirm its safety (Kingsland, 2020). Thalidomide’s developers claimed it provided a breakthrough in safety because overdosing was virtually impossible (Timmermans & Berg, 2003). But German chemical and pharmaceutical firm Chemie Grunenthal had begun to market and distribute the drug to physicians and doctors without extensive testing on laboratory animals (Botting, 2002). Eventually, in 1961, two clinicians independently found that ingesting thalidomide during pregnancy led to severe developmental deformities. By the time the drug was discontinued, it was estimated to cause over 10,000 birth defects and increased rates of miscarriages (Vargesson, 2015).

Another common failure arises when regulators do not or cannot enforce standards independently from the industries they oversee. In 2018 and 2019, for example,

two Boeing 737 MAX planes crashed: one in Indonesia and the other in Ethiopia (Ahmed et al., 2019; Specia, 2018). Even after the second plane crash, the US Federal Aviation Administration (FAA) insisted that there were “no systemic performance issues” with the plane (Kaplan et al., 2019). It reversed course when multiple US and Indonesian aviation investigations concluded that the problem rested with the flight control sensors. Scholars argue that the problem could have been identified much earlier if there had been adequate FAA monitoring after the first crash. However, regulators were slow to identify the problems with the plane because it depended on Boeing and other manufacturers to certify their own planes for design, production, and airworthiness (Kitroeff et al., 2019). Self-certification has been a common practice in the US aviation industry since 2005, and by 2018, Boeing was self-certifying 96% of its aircrafts. In addition, when a Boeing engineer had warned his supervisors that the faulty sensor was inadequate in the 737 MAX, there was no obligation for the company to report this to the FAA (Bellamy III, 2019).

Conflicts of interest have also affected drug approval and regulation. Merck manufactured Vioxx, a pain medication for patients suffering from osteoarthritis, and submitted it, along with the results of studies confirming its safety and efficacy, to the FDA (Food and Drug Administration). Typically, the FDA creates approval committees composed of independent experts, to review new drugs. However, in the case of Vioxx, the FDA allowed conflict of interest waivers for four of six members on the approval committee, all of whom had financial ties

to Merck (Angell, 2015). The FDA ultimately accepted the committee’s recommendation and approved the drug without an external review board to assess patient risks during clinical trials or requiring a Phase IV long-term risk study (Couturier, 2010). Ultimately, the drug increased the risk of serious coronary heart disease, and during its 5 years on the market, it killed an estimated 27,000 people in the United States (Graham et al., 2005). And when an FDA epidemiologist who monitors drug safety confirmed that Vioxx caused an increase in the risk of coronary heart disease, his supervisors pressured him to change the conclusions of his findings (Okie, 2005). Merck finally removed the drug from the market in September 2004.



Credit: FDA (CC-o)

Sometimes, the problem is an organizational one. Experts initially concluded that the space shuttle Challenger exploded in 1986 due to a faulty O-ring, which failed to expand and stop pressurized burning gas from making contact with the fuel tank at low temperatures (Pflugfelder, 2018). But after performing an ethnographic study, sociologist Diane

Vaughan (1996; 2005) concluded that it was the result of a bureaucratic culture that made it difficult for managers to take errors, such as the O-ring problem, seriously. This organizational problem was never addressed and produced the Columbia disaster in 2003. Vaughan argues that there was a “normalization of deviance”, in which small problems were left unseen or dismissed due to NASA’s organizational structure and practices. As a result, once deviance had normalized, it was impossible to act on problems like the O-ring problem in advance (Vaughan, 1996).

## Managing Scientific Uncertainties

Scientific findings always involve some limitations and uncertainties. They are the result of bounded investigations often conducted in controlled environments. These limitations and uncertainties usually matter only to peers in a scientific subfield, who are trying to replicate and build on a

small piece of the world’s storehouse of knowledge. But in cases like vaccines, climate change, or decisions to reopen schools during a pandemic, scientific findings can have enormous, immediate, and widely visible public impact. In these situations—also known as “post-normal science”—the limitations and uncertainties of science are magnified, and it is harder to translate scientific research into a policy consensus (Funtowicz & Ravetz, 1993; Waltner-Toews et al., 2020). A legitimacy crisis for science and scientific institutions can emerge when publics and policymakers depend on limited scientific findings to make decisions, but those results force them to change their lives or compromise their values (Baker, 2016).

“Post-normal science” describes scientific situations in which “facts are uncertain, values in dispute, stakes high and decisions urgent”. It was coined in the context of policies related to environmental risks but is clearly relevant to pandemic science and policymaking” (Funtowicz & Ravetz, 1993, p. 744). Climate change is a classic example: 97% of the scientific community has reached a consensus that climate change is real and caused by anthropogenic greenhouse emissions, and there is grave concern about the global consequences of inaction (Brüggermann et al. 2020; Scientific Uncertainty, 2019). But mitigation and adaptation policies require significant investment and social change, and involve disagreements over values. Furthermore, the climate system and its interactions with humans are complex, so many assumptions might not be factored into predictive models. This then triggers political actors to exploit uncertainties and challenge the scientific



Credit: Artem Podrez



consensus. People who study post-normal science suggest that we should respond with honesty about scientific assumptions and uncertainties, use extended peer communities that include lay people to evaluate new research, better assessments of scientific quality, and better public education about the processes of scientific practice and publication. While some worry that acknowledging uncertainties might lead communities to conclude that scientists are incompetent (Joslyn & LeClerc, 2016), researchers suggest that such honesty increases scientists' credibility (Howe et al., 2019).

The growing reproducibility crisis in science also heightens this sense of uncertainty. Upon repeating 100 experiments published in three high-ranking psychology journals, researchers found that only 36% of the results were statistically significant (Open Science Collaboration, 2015). Additionally, researchers have only been able to replicate 11% of pre-clinical cancer studies (Begley & Ellis, 2012), and half of cancer researchers have been unable to reproduce previously published results (Mobley et al., 2013). Many of the problems at the root of this crisis stem from questionable research practices, where researchers can selectively report results that align with their initial hypothesis (John et al., 2012). They may also

manipulate data collection and analysis to reach statistically significant conclusions. All of this has real impact: publics may hear about the latest psychological or medical research, only to learn later that it was invalidated. Or they may find that it did not work in the context of their own lives and needs.

In approaching the problem of vaccine hesitancy, governments usually take the stance that they must educate the public, because the public's resistance to vaccines must be the result of ignorance. However, the cases above make it clear that often the problem is not a mistrustful public, but rather an untrustworthy establishment. Indeed, the current hesitancy that we are seeing with regard to the COVID-19 vaccine was predictable, and there are steps that both governments and scientific institutions could have taken to prevent it. To effectively address the roots of vaccine hesitancy, scientific and government institutions must first address their failures of communication, regulation, and oversight.

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# Institutionalized Mistreatment of Marginalized Communities

## KEY TAKEAWAYS

- Government, public health, medical, and scientific institutions have long histories of mistreating Black, Indigenous, and other people of color.
- Marginalized communities may approach vaccination campaigns with skepticism because they have rarely benefited from scientific, medical, and public health systems.
- Mistrust among marginalized communities is a product of scientific experimentation without consent, the legacy of scientific eugenics, racist interventions in medicine and public health, and coercive government initiatives.

Scientific, medical, and public health institutions and governments overall have long legacies of mistreating marginalized communities, from the disabled to the resource-poor to people of color. We have already seen how this has shaped the COVID-19 pandemic: Black, Indigenous, and Latinx people in the US have suffered from higher illness and mortality rates compared to other groups (Egbert et al., 2020), while local governments have struggled to control COVID-19 infections among the unhoused (Baggett & Gaeta, 2021). This effect stems

from inequalities in health, healthcare access, and racism in the system (Bajaj and Stanford, 2021). Around the world, members of marginalized groups including immigrant communities tend to have lower incomes, more pre-existing health conditions, and live in conditions that prevent effective social distancing measures from taking place (Evans, 2020). And yet they predominantly comprise the essential labor workforce required for a functioning society, often doing jobs that cannot be completed remotely (e.g. transportation, emergency response, health

care, and agriculture) (Rho et al., 2020). The limited healthcare access, higher levels of exposure to the disease among vulnerable minority populations, and historical entrenchment of racial biases further exacerbate community mistrust of COVID-19 vaccines.

Vaccine hesitancy, then, may become a site of resistance for marginalized communities. Many are skeptical that policy leaders and public health officials are finally paying attention to their participation in the medical system when their needs and perspectives are

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*Limited healthcare access, higher levels of exposure to the disease among vulnerable minority populations, and historical entrenchment of racial biases further exacerbate community mistrust of COVID-19 vaccines.*

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usually ignored. And so, not unlike decisions to engage in other forms of political protest, members of these communities may be willing to put themselves at risk not only because they feel their welfare has never before mattered to experts and policymakers, but also because they may not see themselves as equal partners in the drive towards herd immunity.

## Racism in Science, Technology, and Medicine

Structural racism has profoundly shaped the institutions of science, technology, and medicine, and communities of color are well aware of this legacy. We can see this in the history of infectious disease outbreaks. During the 1793 yellow fever epidemic, Benjamin Rush, a white physician and signer of the Declaration of Independence, argued

that Black Americans were immune (Espinosa, 2014).

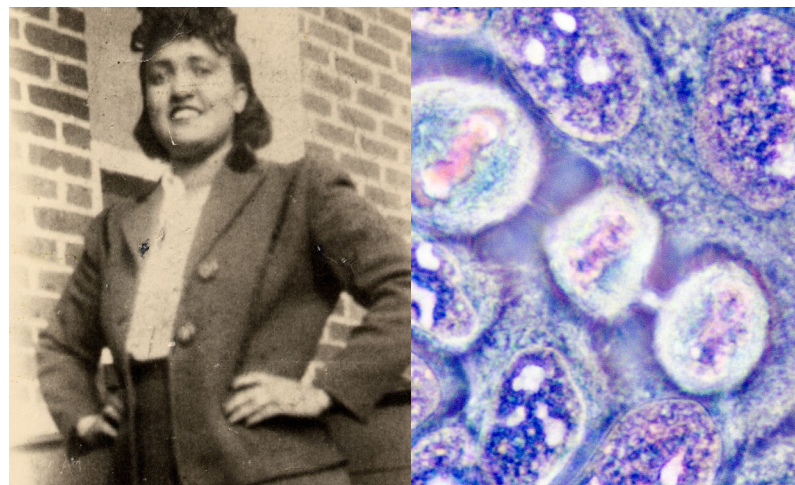
He then persuaded free Black people in Philadelphia to work in essential frontline jobs, including caring for the sick and burying the dead. Even when he learned that Black Philadelphians were dying at the same rate as their white counterparts, Rush claimed that the conditions of the “disease were lighter in them than in white people” despite contrary evidence.

The idea that Black people were somehow less susceptible to infectious disease also clearly played a role in the 1918 influenza pandemic. Many Black people lacked adequate health care and died at home, so their deaths were not counted by local governments. Thus, white people believed that Black workers were immune to the disease, while they were actually suffering disproportionately (Gamble, 2010). Also, legalized segregation

and racism prevented Black patients from accessing adequate health care at better-resourced white medical institutions. However, as with the yellow fever epidemic, Black nurses were pressed into service at overwhelmed white hospitals in addition to providing care at hospitals with a Black clientele. It is important to note that such racism in health care and diagnosis persists today: over the last year, Black Americans have been denied care for COVID-19 because doctors and hospitals did not trust their experiences, and many have died as a result (Eligon & Burch, 2020).

Perhaps most well known is the role that people of color have played as experimental subjects without proper consent. The most famous case is the Tuskegee syphilis study conducted by the United States government beginning in 1932 (Kennedy et al., 2007, Carlisle & Murray, 2020). The study initially involved 600 Black men, 399 with syphilis and 201 acting as the control group. These men were not informed about their disease status or their participation in a study, and were led to believe they were patients in a joint federal and local medical and nursing program and treating them for “bad blood”. The men did not receive and were prevented from receiving proper treatment to cure the illness even when it became widely available. The study continued for 40 years with findings regularly published in academic journals. Despite the efforts of multiple whistleblowers, the government only stopped the study when its details were published in *The New York Times* in 1972 (McVean, 2019). Black Americans often cite the Tuskegee legacy when they describe their distrust in the scientific, public health,

and medical institutions (Freimuth et al., 2001). And, we see similar legacies of racism in other communities of color: at the same time as the Tuskegee study, the United States government was conducting similarly problematic studies of sexually transmitted diseases in Guatemala (Rodriguez & Garcia, 2013).



Left: Henrietta Lacks; Right: HeLa cells culture

The story of Henrietta Lacks has also fomented the Black community’s distrust. In 1951, Lacks visited Johns Hopkins University, one of the few hospitals that treated Black patients at the time, for cervical cancer treatment. Doctors discovered that her cancer cells were particularly durable and replicated quickly, so they isolated them for use in future research studies (Henrietta Lacks, 2020; Skloot, 2010). Her HeLa cell lineage would become the most common cell line in the world and is linked to innumerable discoveries and inventions, including the development of the polio vaccine. But neither Lacks nor her family was informed about any of this use, nor did they receive revenues from any of these developments. Her family only



learned about it when scientists contacted them in the hope that their own cells might be similarly useful. By the 1990s, many members of the Black community knew about Lacks' story and her lack of consent, but it was not until the publication of Rebecca Skloot's book *The Immortal Life of Henrietta Lacks* in 2010 that the story became more widely known. In 2013, the US National Institutes of Health announced that it would give the Lacks family some control over the HeLa DNA sequence and related data, but by then the story had become another example in a long legacy of experimentation on Black Americans without consent or benefit, contributing to their distrust of the scientific and medical establishments (Freimuth et al., 2001; Scharff et al., 2010).

Although the United States and other governments around the world have since implemented regulations to encourage the ethical conduct of research and to ensure diversity among research subjects (Epstein, 2009), racism in science and medicine persists. The biological basis of race has been debunked repeatedly (Saini, 2019), but many researchers still look to biological explanations to understand differences in disease susceptibility and progression, including in the case of COVID-19. These assumptions about biological differences and inferiority are built into our medical technologies. In the case of the spirometer, a technology to measure lung function that is still used today, racial bias is built into the machine itself: it assumes that Black people have lower lung capacity and includes "race correction" software so that this difference can be accounted for in the technical reading (Braun, 2014). This means that a Black person

tested with the spirometer would have to be substantially sicker than a white person in order to be referred for further treatment. Meanwhile, physicians dismiss people of color when they report serious disease symptoms (Chapman et al., 2013).

The long legacy of expert institutions ignoring and even devaluing the concerns of people of color extends beyond health and medicine. Consider the recent water crisis in Flint, Michigan, described in the previous section. Flint residents (who are 54% Black, and have a median income of \$28,834 according to the US Census Bureau) quickly noticed that the water had a bad taste and smell, was discolored, and caused adverse health effects such as hair loss and rashes (Cuthbertson et al., 2016). Despite reporting those conditions, authorities and scientific experts dismissed these complaints (Pauli, 2019). It wasn't until engineering and medical experts translated these warnings into scientific data that they were heard (Morckel & Terzano, 2019; Sobeck et al., 2020). This experience exacerbated feelings of elite and government distrust and alienation in a community that had been experiencing economic hardships, disinvestment, a housing crisis, and infrastructure deterioration for decades (Pulido, 2016; Morckel & Terzano, 2019). It also reinforced feelings of racial injustice, exclusion, and abandonment which manifested as anger and "feeling as though their government officials cared little about them" (Cuthbertson et al., 2016, p. 900; Sobeck et al., 2020). Scholars have identified similar impacts in New Orleans as a result of Hurricane Katrina and its aftermath, when the needs of poor and predominantly Black residents were ignored,

resulting in nearly 2,000 deaths (Cuthbertson et al., 2016; Nicholls & Picou, 2013).

Finally, technologies are rarely developed with the needs of historically disadvantaged communities of color in mind. The National Institutes of Health, for example, spends 500 times more on genetics research than on structural racism and its impacts on health (Krieger, 2005). The pulse oximeter, which monitors a person's blood oxygen levels and can indicate when someone is severely ill, was only tested on white people and is inaccurate on people with darker skin (Moran-Thomas, 2020; Sjoding et al., 2020). Even when technologies might offer some benefits, they are often extremely costly and out of reach for most lower-income people of all races.



*Courtesy: University of Michigan School of Public Health*

## The Legacy of Scientific Eugenics

The legacy of eugenics across the Western world also fomented distrust, particularly among communities of color and disabled

people. Eugenics describes a set of practices and a field of research that began in the 1800s to “improve” the human species through selective breeding. Its aim is to eliminate so-called undesirable traits that range from severe genetic disabilities to benign cosmetic differences and to promote supposedly desirable traits such as strength and intelligence. There have been eugenic practices for centuries, but at the turn of the 20th century, it grew substantially as both a scientific and policy project in the Western world. Most famous is the Nazi regime, which murdered millions of Jews and other marginalized populations (including the disabled, gay and transgender people, and Roma people) with the goal of creating a master race. But eugenics was not just a German preoccupation. American elites adhered to this “science” as early as 1900, convinced that their society could be improved if they could control human breeding. They sought to prioritize the reproduction of some racial and ethnic groups, particularly Nordics and Anglo-Saxons (Stern, 2015; Stern, 2020), over Black, brown, and Semitic groups.

In the United States, it was implemented through forced sterilization of marginalized populations. Thirty-three US states enacted sterilization laws during the first decades of the twentieth century (Stern, 2015). These laws took reproductive freedoms away from women and men of color, incarcerated people, those labeled as “mentally disabled” or “feebleminded”; and it extended further to low-income, gay, or physically ill people. The Supreme Court validated this approach in the *Buck v Bell* (1927) case, which focused on Virginia’s compulsory sterilization of the

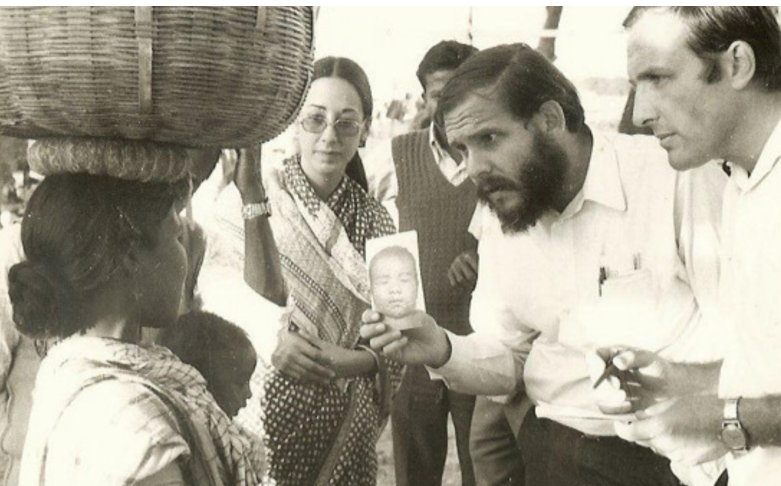
intellectually disabled. The court decided that such laws were appropriate for “the protection and health of the state”. By the 1960s, these laws covered two-thirds of the country and had led to the coercive sterilization of at least 63,000 people (Largent, 2008). Many believe that the actual number is much higher because states did not report numbers if these practices were technically illegal. Patients rarely had the opportunity to approve these procedures and many of them did not even know that they had been sterilized. Similarly, as part of its colonialist project, the US government supported sterilization of poor women in places like Puerto Rico, which served as laboratories to test new sterilization techniques and regulating societies deemed “underdeveloped” through reproduction control (Briggs, 2002). It is estimated that approximately one-third of the female Puerto Rican population was sterilized between the 1930s and the 1970s (Andrews, 2017).

Civil rights activists—particularly women of color—began to challenge sterilization laws in the 1960s, but as recently as the 1990s social welfare programs were still tied to sterilization (Hartmann, 2016; Jacobs, 1992; Licata, 2020). In 2020, the documentary *Belly of the Beast* recounted systematic practices of forced sterilization in Southern California women’s prisons (Cohn, 2020). According to the film, “state audit and prison records reveal nearly 1,400 sterilizations between 1997 and 2013” (Jindia, 2020). Some argue that eugenicist thinking still underpins 21st century public health and social welfare policy (Stern, 2020).

## Coercion to Participate in Government Initiatives

Governments, including public health institutions, have a long legacy of coercing citizens to participate in initiatives designed to contribute to the public good, but that disproportionately hurt marginalized communities. The first sanitary inspectors, employed in England since the 1840s, offer one such example (Mooney, 2020). The government assigned them to both urban and rural localities to prevent disease across the country. Their responsibilities included contact tracing, which involved speaking to people who were afflicted with a disease, recording their contacts, and visiting contacts to warn and encourage them to adopt preventive measures. This was controversial because sanitary inspectors were agents of the state, invested with powers to regulate behaviors in the intimate sphere, and intruding into families’ private homes. Over time, sanitary inspectors became “poor law inspectors” that took charge in promoting personal hygiene in low-income communities, despite the limited access that these marginalized populations had to plumbing and bathing (Crook, 2016). This surveillance role interfered with inspectors’ ability to do effective contact tracing because it eroded public trust. People began to hide or provide misleading information, which in turn prompted inspectors to use coercive sanctions, which include isolation mandates and economic fines (Mooney, 2020), that disproportionately affected the poor and vulnerable communities.

The Smallpox Eradication Program in India and Bangladesh during the 1970s provides an example of coercion for vaccination by an international organization (Greenough, 1995). Both countries were the last to eradicate smallpox, so in 1973, the World



*Credit: University of Michigan Libraries*

Health Organization (WHO) targeted its Smallpox Eradication Program (SEP) towards those nations. The SEP focused its mission on remote villages where smallpox outbreaks needed urgent containment. WHO prioritized comprehensive vaccination in order to achieve total eradication of smallpox. Ignoring the guidance of local officials, the WHO teams dispatched to these villages responded to refusal with coercion, using threats and physical violence to get people vaccinated. While the SEP successfully eradicated smallpox (Henderson, 1987), the coercion and intimidation that characterized the campaign undermined the trust of communities as they felt attacked. The misguided handling of human rights by public

health programs such as the SEP has drawn attention to the need to include human rights considerations when designing public health campaigns (Tarantola & Foster, 2011).

Social welfare programs offer a similar but more contemporary example of mistreatment and deceit that extends beyond the healthcare system and intersects with welfare and justice. Some poverty alleviation programs such as welfare and food stamps include onerous requirements and systems of surveillance meant to control recipients' behavior (Soss, Fording & Schram, 2011). In 1996, the United States passed The Personal Responsibility and Work Opportunity Reconciliation Act (also known as "welfare reform"), which permitted law enforcement officers to use welfare recipients' personal information to "locate and apprehend individuals with outstanding arrest warrants" (Gustafson, 2009, p. 670). The use of this data led to the arrest of 10,980 low-income people throughout the country, mostly charged with minor and non-violent offenses. Known as Operation Talon, it essentially punished poor people for seeking help from the government. Ultimately, this case shows how systems ostensibly designed to help citizens can ultimately increase surveillance and stigmatization, leading to coercion and mistreatment.

Altogether, institutionalized racism in science and technology fields, legacies of scientific eugenics, and histories of institutional coercion to participate in government initiatives are examples of institutional mistreatment that demonstrate why members of marginalized communities

may demonstrate higher levels of vaccine hesitancy. These examples also provide necessary context for recognizing and understanding the ways scientific, medical, and government institutions have continued to fail those communities during the COVID-19 pandemic. We know Black people in the United States are dying of COVID-19 at a higher rate than white people, but due to disparities in access to testing, it is impossible to know the true count (Servick, 2020). Those same disparities are now evident in access to COVID-19 vaccines, with white neighborhoods having more vaccine appointments and vaccination sites that

are easier to access than their Black and Latinx counterparts (McMinn et al., 2021), and vaccine scheduling systems that require access to the internet, a car, and flexible schedules (Shapiro, 2021). Internationally, wealthy countries are hoarding doses and refusing to share with poorer countries until they have first vaccinated their entire populations, prolonging the pandemic globally and inflicting more devastation on populations already ravaged by the disease. Given these institutional failures at all levels, we might be surprised that rates of COVID-19 vaccine hesitancy are not even higher.



# False Information: A Consequence of Institutional Failures

## KEY TAKEAWAYS

- Government failures and misbehaviors produce alienation and distrust, which ultimately makes citizens more susceptible to believing false information.
- Both media fragmentation and the rise of social media are increasing the propensity to see and believe false information.
- False information has an especially high cost for public health and vaccine hesitancy in particular.

The failures discussed in the previous sections alienate communities from the government and the scientific, medical, and public health establishments. In response, citizens may turn to other sources for news and information, such as community leaders, friends, family, or online news sources that they trust, and which fit with their values and presumptions about the world. In some cases, this can lead them to believe false information about vaccines, which ultimately contributes to hesitancy.

The problem of false information is not new, and may be as old as humanity itself, but

communication technologies, from online news to social media, have amplified and accelerated it. People are increasingly getting their news through social media, which might not be subject to professional journalistic scrutiny and is poorly moderated at best (Bergström & Belfrage, 2018). According to a 2017 Pew Research Center report, social media is the main source of news for two-thirds of US adults (Gil de Zúñiga & Chen, 2019). Although some of this content may come from reputable sources, it can be difficult to distinguish between these and less reputable ones. Some estimate that “a false story in the United States reaches 1,500

people six times more quickly than a factual story” (Nemr & Gangware 2019, p. 3).

In the context of public health, false information has a particularly high cost for both individuals and their communities. Public health

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*In the context of public health, false information has a particularly high cost for both individuals and their communities.*

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experts attribute many of today’s infectious disease outbreaks to decreasing rates of routine vaccinations for childhood diseases in the United States and around the world. These lower vaccination rates are in part rooted in false information, such as the notorious Wakefield study which purported to establish a causal link between the measles, mumps, and rubella vaccine and autism in young children (Benecke & DeYoung, 2019). False information about COVID-19’s severity and vaccines has already begun to spread around the world, which could have

## Types of Misinformation

Andrade, 2020; Bruns et al, 2020; Hagen, 2018

### → MISINFORMATION

Misleading information created or disseminated without manipulative or malicious intent.

### → DISINFORMATION

Created with the deliberate and often orchestrated purpose of confusing and manipulating for economic or political reasons, or simply to disrupt public communication processes.

### → PROPAGANDA

A deliberate and systematic effort to manipulate other people’s beliefs, attitudes, or actions.

### → CONSPIRACY THEORIES

A subcategory of misinformation, they provide cohesive and streamlined explanations for a particular event or phenomenon, falsely attributing agency to public or private institutions, individuals, groups of private citizens, or governments. They are also mutually reinforcing, and if people believe in one they are likely to believe in others, and also tend to attribute agency to a single underlying source for all of them. Conspiracy theories are not orchestrated to deliberately deceive. On the contrary, those who believe them often think they have discovered the truth and are motivated by revealing these truths to others. They also serve to unite the audience as “the people” against the imagined “Other”.

disastrous consequences for efforts to reach herd immunity (Rovetta & Bhagavathula, 2020). Our analysis suggests that the histories of government misbehavior, especially in their foreign engagements, and growing political polarization rooted in media fragmentation, create the conditions for belief in false information.

## Conspiracy Theories Rooted in Historical Mistreatment

When communities have experienced the worst, they are more likely to believe the worst, including false information. In Pakistan, for example, US abuse of a vaccination campaign to facilitate the capture of Osama Bin Laden has helped to amplify long-held conspiracy theories. In 2011, American spies posed as vaccinators in Abbottabad, Pakistan to get close to Bin Laden's home and collect information about his whereabouts (Andrade et al., 2018). Shakil

Afridi, a Pakistani doctor recruited by the US Central Intelligence Agency (CIA) to lead the effort, went door-to-door to deliver hepatitis B vaccines. His association with the CIA and his efforts to gather DNA samples under the pretext of delivering vaccines eventually became public, and critically damaged vaccination campaigns across the country (Gostin, 2014). The events fueled the long-standing conspiracy theory that the United States and Israel are actually using polio vaccination programs to sterilize the Muslim population (Andrade et al. 2018). Consequently, militant groups in the region have targeted NGOs and health workers involved in vaccination efforts. Although the Obama administration formally declared that it would stop using vaccine campaigns as a ruse for spy operations in 2014, the damage had been done. Pakistan is still one of three countries affected by polio.

Similarly, the legacies of slavery and Western colonialism continue to engender belief in false information. After centuries of mistreatment, debasement, and being robbed of their labor and natural resources, marginalized communities of color around the world view Western governments with great suspicion. This may make them more prone to "selective exposure", developing a preference for information that confirms their preexisting beliefs, and "confirmation bias," which makes information consistent with one's preexisting beliefs more persuasive (Lazer et al., 2018). Some Black people across the United States and South Africa, for example, maintain that HIV was deliberately created by scientists as a bioweapon to decimate Black populations



Credit: World Health Organization



(Nattrass, 2013). Researchers associate refusal of HIV testing and treatment in some Black communities in the United States, as well as lack of condom use, with belief in conspiracies about HIV's origins (Nattrass, 2013). Given the socio-economic and socio-historic contexts in which Black people around the world find themselves today, this conspiracy theory explains a traumatic event that disproportionately affected this population that aligns with their experiences and knowledge about the world. Paradoxically, refusing medical treatment due to these beliefs leads to poor public health outcomes.

## Government Propaganda and False Information

Governments often work hard to limit and shape publicly available information to maintain their power and legitimacy. However, this can erode citizen trust, which ultimately hurts efforts that require mass participation such as vaccination. In the early 20th century, for example, the British and Australian governments used propaganda to galvanize their civilians to enlist in the army and join the war effort. The governments alleged that during their 1915 invasion of Belgium, German soldiers committed appalling acts of violence against non-combatant Belgians, including women and children (Robertson, 2014). The British and Australian governments used cartoons that dehumanized the Germans and exaggerated the superior moral qualities of the British and the Allies. The campaign was especially successful because it drew

on widely held beliefs about the rights of non-combatants during wartime. After the postwar investigations revealed that these narratives were largely exaggerations, public trust significantly diminished and remained low for decades (Robbins, 2007). During World War II, European citizens distrusted and dismissed Allies' reports about Nazi atrocities, even late in the war (Robbins, 2007).

Propaganda and conspiracy theories can be used as political tools not only in times of war but also in times of peace. In particular, authoritarian regimes have used conspiratorial rhetoric for mobilizing masses, reinforcing current structures of power and authority, and assuring the loyalty of the populace (Giry & Gürpınar, 2020). They also cultivate a belief in the righteousness of the regime and tend to provide comprehensive explanations of complex events. In democratic regimes, conspiratorial rhetoric mainly emerges at the political fringes, while in authoritarian regimes and countries experiencing extreme nationalism, conspiracy theories often stand as objective truths (Giry & Gürpınar, 2020).

## Media Fragmentation and Framing

Media plays an important role in shaping public opinion, especially as it relates to public trust in institutions. It is also crucial in shaping public attitudes to vaccination. Consider Colombia's efforts to vaccinate against papillomavirus (HPV) in the 2010s. Colombia began to vaccinate 9-year old

girls against HPV in 2012 by administering vaccines in schools across the country (Cordoba-Sanchez et al., 2019). After some initial success, about 600 girls who received the vaccine in the town of Carmen de Bolívar reported symptoms (e.g. dizziness and loss of consciousness) that required medical attention following administration (Cordoba-Sanchez et al., 2019).

Both the news and social media widely reported these adverse effects as being a direct result of the vaccine (Cordoba-Sanchez et al., 2019).

After an epidemiological investigation, the Colombian National Institute of Health concluded that the reactions were not due to the chemistry of the vaccines, but rather a mass psychogenic reaction. Despite those conclusions, the event and the media coverage caused a dramatic reduction in HPV vaccine uptake: while in 2012, HPV vaccine uptake among eligible girls were 98% and 88%, for the first and second dose respectively; in 2016 both percentages decreased to 14% and 5% (Simas et al., 2018).

Members of the public rely on media sources to stay informed about their government and the activities of public officials, which makes it one of the key mechanisms for government accountability in democratic nations (Gordon, 2000). But, if media reports lack objectivity or contain incorrect, misleading, or incomplete information, people will be inadequately informed and may lose trust in all media (Gordon, 2000). Research indicates that news in the United States has become more fragmented over time as a wide array

of television news sources has proliferated, influencing the manner in which a large proportion of the American public get their information about politics and government (Morris, 2007). One of the consequences of such media fragmentation is polarization of US television news audiences (Morris, 2007).

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### *Increasingly, news sources cater to specific demographics and preexisting belief systems.*

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Increasingly, news sources cater to specific demographics and preexisting belief systems, moving further away from the earlier journalistic ambitions of objective and factual reporting. For example, in the United States, the Fox News Channel appeals to individuals with politically conservative views who have become disillusioned with what they perceive as a liberally biased mainstream media (Morris, 2007). On the other end of the spectrum, MSNBC appeals to an audience that holds left-leaning political beliefs. This growing heterogeneity of news and strategic appeal to certain audiences calls into question media objectivity and reinforces beliefs in media bias (Morris, 2007). This can have huge impacts on the information that members of the public receive about vaccines.

At the same time, customary standards for media objectivity are themselves biased. According to a research project by the Center for Media Engagement, which looked

at sources of new media distrust among Black Americans, mainstream journalism fails to meet the standards of this audience (Wilner et al., 2020). The respondents in the study noted that what really influenced whether Black Americans trust the news media was “how well they felt the media covered their communities, and, to a lesser extent, how diverse they felt newsrooms were”. Many expressed that news coverage of Black communities is often one-sided and incomplete, and although they do trust journalists in general, they do not necessarily trust journalists to cover Black communities accurately.

Overall, both government and media institutions have a crucial role to play in shaping vaccine hesitancy. Cruel and unethical government behavior—from

authoritarianism to exploitation of foreign citizens—leads to alienation and distrust and ultimately receptivity to false information. Similarly, media fragmentation has led citizens to seek information that aligns with their preconceived beliefs while questioning reporting that challenges them. This too leaves already skeptical publics to become more hesitant to believe governments that they distrust. We have already begun to see the consequences in the case of COVID-19; in the United States, 49% of Republican men say they do not want to get vaccinated (Summers, 2021).

# Conclusion: The Roots of Vaccine Hesitancy

After examining a range of analogical case studies, we conclude that vaccine hesitancy does not stem from public ignorance, but rather public mistrust of institutions. This is rooted in both historical legacies and ongoing mistreatment. First, science and technology institutions have, on multiple occasions, failed to consider and uphold public interests. Second, scientific, medical, and public health institutions, as well as governments generally, have long legacies of mistreating marginalized communities. As a result, citizens mistrust elite institutions and turn to their communities for information and answers. False information is often the result.

Science and technology institutions have failed publics in multiple ways in recent decades. While regulatory processes and thresholds may reflect scientific consensus, they do not represent community knowledge or expertise. Not only does this alienate publics, but institutions often lack knowledge and expertise relevant to decision making. Lax regulation and problematic bureaucratic cultures have led to high profile technological disasters. Finally, poor communication about the limitations and uncertainties of scientific research creates public mistrust over the accuracy and relevance of “evidence-based” recommendations.

Structural racism has shaped the fields of science, technology and medicine, not just in the past but even today. Expert institutions regularly ignore and devalue the expertise



*Credit: Phil Roeder (CC BY 2.0)*

and concerns of people of color, which further erodes trust between institutions and marginalized communities. The eugenic ideals of white supremacy remain embedded in our current public health and social welfare policies. Government and public health institutions coerce people to participate in initiatives in the name of serving the public good while disproportionately hurting marginalized communities. Thus, marginalized communities may be skeptical of vaccination campaigns, and even refuse to participate because their needs and perspectives have been ignored for decades.

Ultimately, institutional mistrust leads publics to seek alternative sources of information, particularly those that fit with their pre-existing beliefs. This becomes a breeding ground for false information. Meanwhile, with media fragmentation and the rise of social media, false information has become more readily available. And, governments erode citizen trust when trying to limit and shape publicly available information to maintain their power and legitimacy. This contributes to a feedback loop that makes the skeptical communities even more hesitant to believe in governments they already distrust.

Based on this analysis, we provide a series of recommendations to help governments and publics improve institutional trust. In particular, institutions must create more

trusting relationships with publics by learning about and listening to community concerns and welcoming their expertise, increase research and educational funding on the relationships between health and society, and improve institutional accountability and oversight. Overall, these recommendations should not only minimize vaccine hesitancy, but also facilitate other public health, social, and environmental initiatives. For each recommendation we offer a model case where this idea has been implemented well.

# Recommendations

Throughout this report, we have focused on how institutional failures in science, medicine, public health, and government overall have cultivated mistrust among publics and are likely to produce vaccine hesitancy. In this section, we offer recommendations to reverse this mistrust. Many of these recommendations can be used to overcome current vaccine hesitancy and manage the COVID-19 pandemic. However, addressing institutional mistrust requires systemic investment, so we have offered long-term solutions as well. **We envision that these recommendations will not only help manage this pandemic and improve vaccine rollout, but also have broader impacts in enhancing public trust in science, technology, medicine, and public health.** To help policymakers, public health officials, and other stakeholders imagine how to implement these recommendations, we offer model cases where such solutions have been implemented successfully.

## Building Community Trust

### RECOMMENDATIONS

#### 1

#### RECOMMENDATION 1

In the short term, public health officials should develop vaccination initiatives in partnership with local institutions (e.g., schools, houses of worship, community centers, sports leagues) that community members already trust. Information should be culturally relevant and appropriate (and in multiple languages as appropriate), described simply, and in formats that are accessible to people with disabilities.

#### CASE 1

To reduce the disproportionate impact of HIV and STDs in **North Carolina's Latino population**, public health officials and community leaders identified **local soccer teams** as a key social network that had already established trusting relationships. Public health officials and community leaders then worked with the teams to develop an intervention program and educational materials in Spanish, which focused on condom use and HIV testing. Advisors in the intervention program were trusted members of the community and became the predominant sources of reliable information on sexual health within social networks. This strategy was effective in reaching these communities and continued to promote resources to reduce infection rates even after the conclusion of the initial study. (Rhodes et al., 2016).



## 2

## RECOMMENDATION 2

Proactively ensure that vaccination sites are located in marginalized communities (especially because these communities are often at the highest risk of adverse outcomes).

## CASE 1

The **Black Doctors COVID-19 Consortium** (created in April 2020) assembled a network of volunteer Black doctors and nurses to create a mobile clinic to offer COVID-19 testing. The clinic, which operated out of a minivan, moved from church parking lots and busy street corners in Philadelphia, PA to ensure that people who might not have easy access to primary care physicians and who rely on public transportation would have access to COVID-19 tests (Feldman, 2020).

## 3

## RECOMMENDATION 3

Scientific, policy, and public health institutions must develop community trust for the longer term. To do this, they must build ongoing partnerships with communities and their leaders to create deep relationships and facilitate a two-way flow of knowledge. Public engagement efforts should be designed to listen to community needs and concerns rather than “educate,” with the recognition that publics have expertise. Let people ask questions and give honest responses, which can enable more active participation and allow communities to ask for what they want to see in vaccine distribution and development.

## CASE 1

After Hurricane Katrina devastated Harrison County in Mississippi, the Congress for New Urbanism and the Mississippi Governor's Commission on Recovery, Rebuilding, and Renewal hosted the **Mississippi Renewal Forum** to plan for coastline rebuilding. This project brought together residents, public officials, and members from Ohio State University (OSU) to develop solutions to community problems together via town hall meetings. In preparation for these meetings, volunteers mailed newsletters to every property and sent flyers with meeting details through elementary school students. This resulted in very high attendance. At these meetings, the OSU team used a Visual Preference Survey to let community members vote on pictures of what they want as an outcome of the community project. This approach helped county officials, volunteers, and community members come together to enable participatory solutions for rebuilding the community (Evans-Cowley & Gough, 2008).

## RECOMMENDATION 3, CONTINUED

**CASE 2**

The **Healing of the Canoe (HOC) Project** was a research partnership between the Suquamish Tribe and the University of Washington Alcohol and Drug Abuse Institute to develop and implement a needs and resources assessment, focused on preventing substance abuse and strengthening the sense of belonging to the community and tribal identity among youth. To build a long term and mutually beneficial relationship between the community and scholars, the HOC project used a community/tribal participatory approach through which they identified the main issues of concern for the community (in this case these were youth substance abuse and loss of their sense of belonging to the Suquamish community), and the community strengths and assets to address those concerns (extended families support systems). The success of this intervention allowed the community and scholars to set research agendas and health promotion programs respecting tribal sovereignty collaboratively, and incorporate indigenous traditions and strengths (Thomas et al., 2010).

**CASE 3**

Six academic research programs from UCLA, RAND Health Program, and the Charles R Drew Medical University created a partnership with five public healthcare partners and two community organizations from Los Angeles County to identify community priorities and challenges in public health-related issues, while achieving research progress to reduce health disparities. Called the **Los Angeles County Community Health Improvement Collaborative (CHIC)**, members determined four priorities—depression, psychological consequences of exposure to violence in children, obesity, and diabetes—and then elicited community perspectives on these priorities through a roundtable exercise. Ultimately, it created 26 research projects. Over the long term, CHIC will develop capacity for sustainable partnerships and ongoing program and research development (Wells et al., 2006).

## 4

## RECOMMENDATION 4

At all levels, from government leaders to the lab, encourage and facilitate honest communication about scientific limitations and uncertainties. Communicate clearly about the processes of vaccine review and approval and ensure that community knowledge and expertise is integrated into these processes. Commit to transparency about the risks of the vaccine and acknowledge the unknown.

CASE 1

During the COVID-19 pandemic, the **National Medical Association (NMA)** (the US's largest organization of Black physicians) created an independent task force to review the clinical trial data for COVID-19 vaccines and look for discrepancies in the data that could disproportionately affect the Black community. Additionally, the NMA provides guidance to the Black community through meetings and webinars organized with churches and universities. The NMA COVID-19 task force listens to community concerns, poses these questions to vaccine manufacturers, and provides follow-up answers in subsequent meetings. The ability to question and receive answers regarding personal risks of the vaccine directly from the manufacturers has helped community members gain trust in the technology (Boodman, 2021).

CASE 2

In the wake of Hurricane Katrina, the city of New Orleans implemented the “**NOLA Ready**” system for its disaster preparedness and response. The system auto-calls, texts, and emails residents about hurricanes and floods, and tests methods in advance to ensure clarity in communication. Its website serves as a portal for information about disaster preparedness and understanding hurricane and flood risks. It has also taken a leadership role in responding to COVID-19, in terms of informing citizens about testing sites, encouraging them to stay home, and assisting needy residents with meals (NOLA Ready, 2021).

## 5 RECOMMENDATION 5

**National governments should fund local level public engagement (rather than national education campaigns).**

### CASE 1

The US 2020 Census relied on a network of community-based organizations to promote participation and increase overall counts. The **Complete Count Committee programs (CCCs)**, run by local government officials at the city and county levels, included representatives from a wide range of social, political, and economic sectors, including churches, religious groups, unions, local businesses, service-providers, and civil rights organizations. By delegating decision making, this approach allowed for flexibility to address specific local challenges and led to innovative strategies. In New York City, BronxWorks, a local nonprofit, partnered with food pantries to increase face-to-face engagement with the hard-to-count population. The Boro Park Jewish Community Council reached the historically undercounted Jewish Orthodox community in Williamsburg by asking a marketing firm to compose a Census-themed Yiddish jingle. They then played the message while driving around Williamsburg amid COVID-19 lockdowns to promote census participation (Dowd & Sandoval, 2020).

### CASE 2

During **Colombia's 2018 Census planning and operation**, the National Administrative Department of Statistics of Colombia provided funding to and worked with local communities to develop independent, culturally appropriate plans to encourage indigenous and African descendent communities to participate. Community organizations designed and disseminated their own communication campaigns, according to their customs and languages. These organizations also led census operations in their territories by managing tasks such as data collection with their own census takers, and transportation organized by the community. This approach yielded a more accurate account than the previous census in 2005, and at the same time, community leaders developed basic demography skills so they could use census data in their organization and advocacy processes (Departamento Administrativo Nacional de Estadística, [DANE], n.d.a.; Departamento Administrativo Nacional de Estadística [DANE], n.d.b; Economic Commission for Latin America and the Caribbean [ECLAC], 2011; Economic Commission for Latin America and the Caribbean [ECLAC], 2019).

## 6 RECOMMENDATION 6

Local and state governments should create regular deliberative forums (virtual or in-person) to incorporate community perspectives (particularly those from historically marginalized communities) into day-to-day policymaking. This will help to simultaneously improve decision making and establish closer relationships and trust in the long term.

### CASE 1

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The Taiwanese government developed a virtual platform that lowers the barriers to democratic participation and gives citizens greater agenda-setting powers (Tang, 2019; Sifry, 2018). On the **vTaiwan** site, citizens can rate and comment on every item in the national budget. Additionally, the platform allows for citizen-driven petitions for agendas of interest. Once an e-petition has over 5,000 signatures, ministries must respond and hold meetings with citizens to resolve issues. Major accomplishments include improving the experience to file income taxes, balancing marine biodiversity in national parks, and allocating medical resources to remote towns.

### CASE 2

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The New Zealand government developed **Ask Away**, an online forum that enables youth to become more involved in local and national politics. Young voters can ask about, vote, or endorse policies and political agendas. During the election cycle, over 22,000 New Zealanders (equivalent engagement to 1.8 million young US voters) across 9 different political parties came to the site and asked over 1,000 questions. This online forum helps promote civic engagement among young voters by making policies more transparent and accessible (Howie, 2015).

## Research & Education Funding

### RECOMMENDATIONS

# 7

#### RECOMMENDATION 7

Provide additional research funding for and enable community-driven research to investigate community public health and medical priorities, and ensure that the research insights developed inform public health practice and policy.

#### CASE 1

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The **Healthy Flint Research Coordinating Center** is an example of research driven by community priorities. All research conducted in Flint, Michigan must be reviewed and approved by the Center, which has deep ties to the city's large African American community. In return, the Center helps to promote the work among possible participants and helps researchers secure funding (Key et al., 2019). This process ensures that the concerns of Flint residents drive the research agenda.



## 8 RECOMMENDATION 8

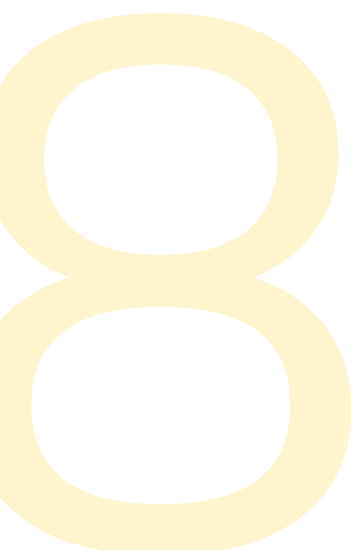
Fund training and support programs to enable people from marginalized communities to become doctors, scientists, and public health officials, and fund evidence-based efforts to make those fields more open to these communities.

### CASE 1

The **Association of Black Women Physicians (ABWP)** focuses on improving public health and welfare-related to women and community health. Since its inception in 1982, ABWP has awarded over \$700,000 in scholarships to Black medical students. In addition to scholarships, its “Sister-to-Sister” mentorship program provides needed support and connection to Black women interested in becoming healthcare professionals. The program’s primary focus is to mentor pre-medical school and medical school students as they navigate through school and job applications as well as their technical training (ABWP, 2021).

### CASE 2

Established in 1996, the **Centre for Aboriginal Medical and Dental Health (CAMDH)** at the University of Western Australia (UWA) works to improve recruitment and retention of indigenous medical students, including Aboriginal and Torres Strait Islander people. It also assists Medicine and Dentistry departments in teaching about Aboriginal health and building connections to Aboriginal organizations. Through these connections, CAMDH is able to solicit and incorporate indigenous perspectives into curriculum development and delivery, reflecting community values, knowledge, and processes (CAMDH, 2021). Importantly, the program supports alternative entry schemes that assess students’ ability using a wider range of criteria than those used in conventional academic programs. By the end of its first decade, the program graduated 11 Indigenous doctors and had 23 Indigenous students enrolled (Lawson et al., 2007).



## 9 RECOMMENDATION 9

Create a national initiative focused on health disparities and health research that centers the lives, bodies, and experiences of historically disadvantaged communities of color and addresses disincentives to doing this type of research. This should include both biomedical and social science research, into, for example, structural inequalities in healthcare. This research should then inform public health practice and policy.

### CASE 1

The **Manhattan Project** was a collaborative effort by the United States and the United Kingdom during World War II. This \$2.2 billion (\$23 billion in 2019 dollars) project introduced discoveries on atomic weapons, emphasized the importance of relating physical sciences to national security, and employed over 130,000 people (Lee, 2012). It was crucial to the war effort.

### CASE 2

In 1988, President Reagan and the US Congress provided the National Institutes of Health and Department of Energy with \$2.7 billion (\$6.7 billion in 2021 dollars) to work on the **Human Genome Project**. The international project, which was dedicated to mapping and sequencing the human genome, is still the world's largest collaborative biological research project. This program also included dedicated funding for research into the ethical, social, and legal implications of this research. It completed its work in 2000 and its findings have had a major impact on both genome science and technology (Cook-Deegan, 1996).

## 10 RECOMMENDATION 10

Fund social science research dedicated to understanding past institutional failures and preventing future failures, and use this to inform organizational and bureaucratic culture and practices.

### CASE 1

The **US National Science Foundation** already has programs focused on Science, Technology, and Society and the Science of Science, but results of their research are not well integrated into science and technology policymaking. Research into the 1986 Challenger space shuttle disaster revealed organizational and cultural problems at NASA, which if addressed earlier could have prevented the 2003 Columbia disaster (Vaughan, 2005).

## Accountability & Oversight

### RECOMMENDATIONS

# 11

#### RECOMMENDATION 11

Create effective accountability structures at the national, state, and local levels for people who perpetrate bias in medicine, alongside an effective grievance structure for people who experience bias in medicine. This would include a clear and public accountability process for failures.

#### CASE 1

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In the United States, **Title IX of the 1972 Education Amendments** is intended to protect people from discrimination based on sex in education programs or activities that receive federal funds, including federal financial aid for students. It was recently revised to include detailed requirements for a formalized reporting and grievance process for sexual harassment that all educational institutions receiving federal financial assistance must implement. The rule “requires schools to investigate and adjudicate formal complaints of sexual harassment using a grievance process that incorporates due process principles, treats all parties fairly, and reaches reliable responsibility determinations” (United States Department of Education, n.d.). It further requires training of relevant staff, written documentation and record-keeping, and freedom from coercion. The new rule is based on complaints related to some institutions’ inconsistent responses to complaints of sexual harassment. It aims to improve accountability and victim safety and support.



# 12

## RECOMMENDATION 12

Ensure that vaccine regulatory processes are transparent and that citizens have the opportunity to participate. They should be included on vaccine advisory committees.

### CASE 1

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**Patients' Tumor Bank of Hope (PATH)** is an independent non-profit foundation established in Germany with the purpose of supporting breast cancer research with high-quality tumor tissue. It achieved substantial transparency by publishing the results of studies performed with collected samples on its website. This allows patients to directly see what their samples have achieved. Additionally, PATH biospecimen donors receive a yearly newsletter, covering topics like clinical studies, new therapeutics, and progress in research and development. The biobank also relies on its board, composed of three breast cancer survivors, for representation, research direction, and other activities (Mitchell et al., 2015).

### CASE 2

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Patient inclusion in peer review of scientific publications can improve the usefulness and relevance of patient-centered outcomes research. In 2016, the **Patient-Centered Outcomes Research Institute (PCORI)** established a **Peer Review Program** in the United States to provide opportunities for patient engagement in the scientific pre-publication peer-review process. In particular, they are brought in to assess the feasibility and attractiveness of particular interventions from a patient perspective. Since the program's inception, 175 patient, caregiver, and patient advocate reviewers have provided insights and recommendations on over 280 PCORI-funded research reports, often making improvements and suggesting patient-oriented modifications to presentation of results (Vander Ley & Ivlev., 2021).

### CASE 3

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The **European Medicines Agency (EMA)** is an agency of the European Union responsible for the evaluation and supervision of medicinal products. Since 2007, EMA has routinely invited patients and representatives from patient-advocacy groups to share their experiences and perspectives on particular medicine in their disease area. By organizing patient-led scientific advisory panels, EMA can advise drug developers and regulators on what the patient group considers to be important. Patients are invited to participate either through written feedback or by attending face-to-face meetings. Based on patient advisory board outcomes, 27% of EMA's recommendations were modified to reflect patient perspectives (EMA, 2019).

# 13

## RECOMMENDATION 13

Government (ideally at the national level) should require physicians to report adverse events linked to vaccines, and fund and create processes for better data collection of adverse events.

### CASE 1

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In Germany, pharmaceutical companies, physicians, and pharmacists are legally obligated to report suspected adverse reactions of any substance considered a medicinal product. These professionals report cases to the **Drug Commission of the German Medical Association (DCGMA)** and the Federal Institute for Drugs and Medical Devices (BfArM), those who run the “Medical Committee for Drug Safety” (ÄAAS). This Committee receives reports of adverse drug reactions and maintains a joint database for suspected adverse drug reactions. This data, in turn, is the basis for drug safety monitoring and improvement. (Federal Institute for Drugs and Medical Devices, n.d.a); Federal Institute for Drugs and Medical Devices, n.d.b).

# 13

## 14 RECOMMENDATION 14

Scientific and science policy institutions (e.g., research funding agencies, universities) should increase participation of marginalized communities in oversight committees, including reviews of ethical and scientific aspects of study protocols.

### CASE 1

The NorthShore University HealthSystem Research Institute and the Lake County Health Department/Community Health Center, based in Illinois, established **CACHE**, a Community Advisory Committee to advise researchers on their public health work. Together, they created innovative strategies to overcome community mistrust in medical research; for instance, they increased male participation in research that requires biospecimen collection to analyze “stress and resiliency over time and their impact on mothers’ and fathers’ physiology” (Shalowitz et al., 2009).

### CASE 2

The **Wales Cancer Bank (WCB)**, a cancer tissue biobank hosted by Cardiff University, relies on patients working alongside professional staff to ensure the bank’s success. Four lay members (3 patients, 1 caregiver) comprise the core of the patient and ethics committee, which drafts the ethics application, the patient information materials and consent forms, and advises on proposed patient engagement. They also share responsibility for reviewing lay summaries of the studies that use WCB samples to ensure that they are understandable to a general audience. This means that no researchers will receive biological samples until the reviewing ethics committee member is satisfied that the content and structure of the lay summary describes the proposed research in comprehensible terms (Mitchell et al, 2015).

## 15 RECOMMENDATION 15

Provide regulatory oversight for social media and news outlets to reduce misinformation and disinformation.

### CASE 1

Create social media regulatory oversight analogous to the **Fairness Doctrine**, which required broadcasters to set airtime for controversial issues and provide contrasting arguments. The goal of the Doctrine was to ensure that the target audience would be able to hear views from opposing sides of controversial arguments. Implementing an updated Fairness Doctrine beyond broadcasting can moderate biases in news coverage and retain American trust in public media (Klein, 2020).



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