EXECUTIVE SUMMARY

# In Communities We Trust

## Institutional Failures and Sustained Solutions for Vaccine Hesitancy

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**TECHNOLOGY ASSESSMENT PROJECT** REPORT

# About the Authors

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**Margarita Maria Rodriguez Morales** is a Ph.D. student in the Public Policy and Sociology Program at the University of Michigan. She holds an MA in Science and Technology Studies and a BSW, both from Universidad Nacional de Colombia. Her research interests focus on inequalities, state intervention, development, and science and technology studies. Margarita is currently studying the bureaucracies that govern poverty in Latin America. She has a particular interest in the social construction of poverty metrics, and their implications for poor populations and the relationships between citizens and the state.

**Kseniya Husak** is a dual-degree masters student in the Public Policy and Information Science Programs at the University of Michigan. Her studies are focused on energy policy, program evaluation and data science. Before attending graduate school, she helped administer low-income solar programs in California. While in graduate school, she participated in a range of research projects, focused on automatic detection of online misinformation, brownfield redevelopment, and transportation and renewable energy policy landscapes in Wyoming. Upon graduation, she hopes to continue working at the intersection of energy, policy and technology.

**Molly Kleinman** is the Program Manager of the Science, Technology, and Public Policy program at the University of Michigan, and a lecturer at the University of Michigan School of Education. She studies higher education policy, access to information, and faculty experiences with technology. Molly spent several years as an academic librarian at the University of Michigan, and served as program manager for clinical and basic science education at the University of Michigan Medical School.

PDF: Click to return to top

Molly received her Ph.D. in Higher Education Policy from the University of Michigan Center for the Study of Higher and Postsecondary Education, with a certificate in Science, Technology, and Public Policy, her MS in Information from the University of Michigan School of Information, and her BA in English and Gender Studies from Bryn Mawr College.

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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.

PDF: Click to return to top

# 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.

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

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)*

PDF: Click to return to top

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 “feebleminded”. 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.

PDF: Click to return to top

## 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.

PDF: Click to return to top

RECOMMENDATIONS

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.

PDF: Click to return to top

## 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.

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.

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.

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.

PDF: Click to return to top

## 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.

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

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.

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.

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

PDF: Click to return to top

## VIEW THE FULL REPORT

## myumi.ch/VaxTrustReport

If you would like additional information about this report, the Technology Assessment Project, or University of Michigan's Science, Technology, and Public Policy Program, you can contact us at **stpp@umich.edu** or **stpp.fordschool.umich.edu**.

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