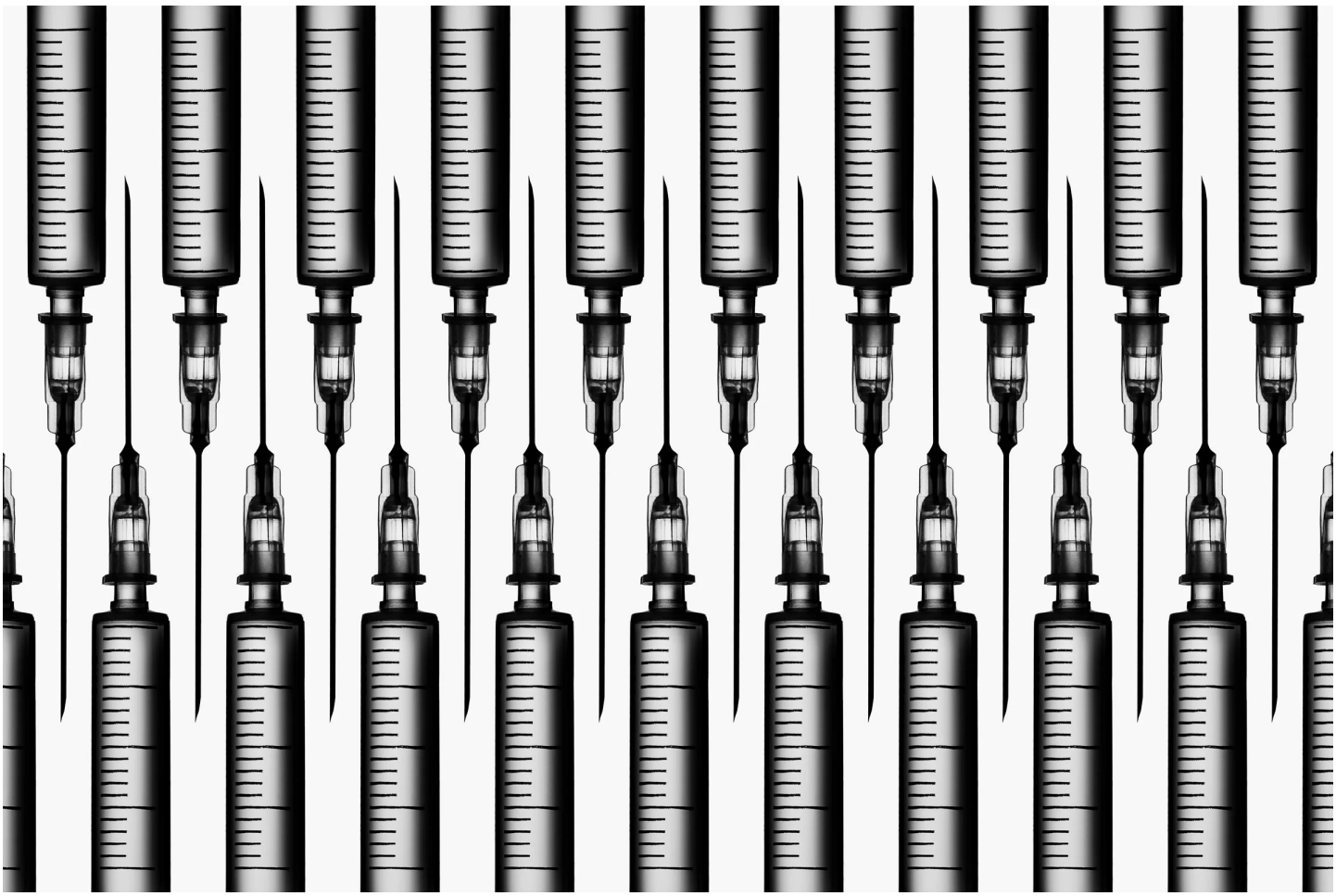
MARYN MCKENNA SCIENCE 11.02.2020 07:00 AM

Winning Trust for a Vaccine Means Confronting Medical Racism

The US has a long history of abusing minorities for pharmaceutical profit. Messaging for a Covid-19 inoculation will have to overcome that past.



As the US government scrambles to protect its residents from Covid-19, it is simultaneously having to confront and try to unwind decades of justified distrust. PHOTOGRAPH: WESTEND61/GETTY IMAGES

WHENEVER THE UNITED States gets access to a coronavirus vaccine—and that hoped-for date keeps shifting, from the White House's boasts of achieving it before the election to Anthony Fauci's estimate of maybe January—one early push will involve getting the shot to people most in danger of becoming seriously sick or dying from Covid-19.

That is looking more difficult all the time, and not only because of the calendar. Some people—and this includes state governors—are concerned that vaccine approval may be fast-tracked for political benefit. But others are suspicious of a vaccine because of well-documented mistreatment of members of minority groups in medical research.

Polls already show rising suspicion of the vaccine, even though, at this point, none of the candidates have been approved by the Food and Drug Administration and no final data about safety or efficacy has been released. Several national polls taken since the summer show that up to two-thirds of people plan to wait at least several months after a formula becomes available, to see whether adverse reactions occur. One-quarter to one-third of poll respondents said they plan to never take the vaccine. As the US government scrambles to protect its residents from Covid-19, it is simultaneously having to confront and try to unwind decades of justified distrust.

"Our message can't be that we are shaming people for not being interested, or making them feel bad for not protecting their health," says Margot Savoy, a physician who chairs the Department of Family and Community Medicine at Temple University's Lewis Katz School of Medicine. "People are saying no because they are genuinely afraid. And if you dismiss people's fears without helping them to have a reason to trust you, we will lose them—and not just for this vaccine."

Responding to that hesitancy, several groups have announced recently that they plan to make their own reviews of the vaccine data once it becomes available. The National Medical Association, a professional society for African-American and Black physicians, announced in September that it is creating a task force to scrutinize any vaccines that receive the FDA's emergency-use authorization, a shortcut to a traditional new drug approval. A few days later, Governor Andrew Cuomo created a vaccine review commission for New York state. Then, in October, Governor Gavin Newsom announced that California

would also independently review safety data before allowing any new vaccine to be given there. Oregon, Washington, and Nevada joined the California effort last week.

So whichever vaccine arrives first, skepticism will be waiting for it. Researchers and public health planners, already snarled in how to manage the fastest vaccine-research program in history, are trying to think through how to mitigate that. "Ensuring that the data is transparently made available to the public as quickly as possible will be really critical as far as reassuring the public about the safety and efficacy of the vaccines," says Evan J. Anderson, a physician and professor at Emory Medical School and an investigator in Emory's Vaccine Treatment and Evaluation Unit, which is conducting several Covid-19 vaccine trials. "But at some level, it will be hard to completely reassure people until larger numbers of people actually receive the vaccine."

This gets tricky, because it is almost certain that some recipients of the new vaccines will experience some kind of transient reaction to them—not necessarily the very serious side effects that have shown up once per 100,000 or 1 million doses in past vaccine campaigns, but fever, fatigue, and muscle and joint pain.

We know this is likely, even though there is no comprehensive data yet, because some recipients have described reactions in media reports, and two companies, Pfizer and Moderna, documented reactions in medical journal accounts of their small Phase I safety trials. Plus, some of the vaccines we take all the time come with brief reactions after inoculation. Flu vaccines cause headache, muscle ache, and fatigue in up to a third of adult recipients, and "flu-like illness" (not the actual flu, but a sign of the immune system reacting to the antigen) in 5 percent of older people with chronic illnesses. And the vaccine against shingles is notorious for aftereffects; the Centers for Disease Control and Prevention tells people who take it that they will likely be slowed down for 2 to 3 days.

One of the challenges of putting out messages about the new vaccine, Anderson says, will be convincing people that any similar symptoms aren't a danger signal. "That's not a safety issue; those are expected reactions," he says. "A safety issue is: Are there issues related to receiving the vaccine that put you at increased risk of hospitalization or unusual events?" A safety issue, for instance, would be the occurrences of Guillain-Barré paralysis that followed the 1976 swine-flu inoculation, or the cases of narcolepsy that occurred after some children in Europe received the 2009 H1N1 flu vaccine—not whether you feel flu-ish and have a sore arm.

So, reactions may be common, and they may be misunderstood. Now layer that reality on top of two other phenomena. One is that racial and ethic minorities in the US have experienced higher rates of illness and death from Covid-19—and because of that, some experts argue they should go to the front of the line to receive the new shot. The other is that throughout US history, those same groups have been subjected to medical racism, used to test techniques and treatments, or the withholding of treatment, for someone else's benefit. In other words, the people who might need the vaccine the most might also have the most reason to be suspicious of it—and yet, if they refuse it, might be the most likely to suffer the worst effects of the disease.

Just about every minority group residing in the United States can point to what feels like a reasonable basis for suspicion. For African Americans, there is not only the notorious Tuskegee study, which withheld syphilis treatment from rural Black men, but also experiments that used enslaved women to perfect surgical techniques and studies that tested new drugs in poor neighborhoods without adequate consent. The Latino community can point to a syphilis study in Guatemala that was even more unethical than the Tuskegee one, and to pharma companies basing tests of the first versions of birth control pills, which caused significant side effects, in Puerto Rico (and also in Haiti). Attempting to pass smallpox to Native Americans via contaminated blankets is an infamous episode in Colonial-era history, and the US government has underfunded the Indian Health Service since its 1955 founding, depriving reservation dwellers of what should have been guaranteed medical care.

"People really feel right now, in our communities, that we're being used as guinea pigs to create something that will benefit others," says Abigail Echo-Hawk, a citizen of the Pawnee Nation of Oklahoma who is chief research officer at the Seattle Indian Health Board and director of the Urban Indian Health Institute. Though the Covid-19 vaccine trials sponsored by the National Institutes of Health attempted to recruit Native American participants, the rush to enroll them quickly just made distrust worse, Echo-Hawk said. "People were feeling that they are being coerced into it, which is the opposite of informed consent. So when we actually do have a vaccine, as a result of these missteps, we're going to have to really address the safety component of it. Because right now, the fear is the worst I've ever seen."

Moving too fast and not paying attention to a minority group's history with the government is causing problems for reaching Latino groups as well, says René F. Najera, an

epidemiologist who teaches at Johns Hopkins University and George Mason University. So is not understanding that, within an ethnic group, not everyone has the same concerns. "For the Mexican and Central American cohort, the concern is: Am I going to be asked to produce papers? Am I going to have to register on some database?" says Najera, whose family is originally from Mexico. "Permanent residents are worried about the Trump administration and the change to the public charge rule; they are fearful that using the health department or getting your vaccines could keep them from becoming citizens. And then within the Puerto Rican community, there's a memory of unethical medical practices."

Savoy, who is African American, sees patients at a clinic in North Philadelphia, in a historically poor zip code. Every year, she says, she has heard concerns about flu shots from some of her patients: worries about what the shot contains, fears that people are being used as test subjects. News coverage of the White House's push to get the Covid-19 vaccine out quickly—even the name of the effort, "Warp Speed"—has made all that much worse.

"People say, 'I always was suspicious that the government was trying to do stuff to me. And now I'm seeing on TV, the government is clearly doing things that don't seem aboveboard,'" she says. Among her Black patients are grandparents who are old enough to have been included in the Tuskegee study, which was launched in 1932 and didn't end until 1972, four years after a whistleblower made it public. "They will tell me that there are certain things that they will trust me on, and certain things that they love me for, but they just know that I'm just not old enough to know any better yet," Savoy says.

Among her white patients, Savoy adds, there is similar distrust—not from any significant scandal such as Tuskegee, but from the experience of being a poor person in America. "They have been in situations where they feel like the government or society didn't protect them," she says. "And they see this as another situation where they can be harmed."

So to get to vaccine acceptance, public health planners have a lot of work to do. That includes taking the time to refine messages about vaccine safety that acknowledge the harms done to minority communities in the name of health. It also includes identifying the channels where people are now likely to encounter misinformation—from Facebook or WhatsApp or local radio—and finding people who can deliver credible messages on them. That probably doesn't mean members of the government public health establishment, but it could mean local physicians or community health workers or influencers. Or people who

occupy more than one of those categories, such as the doctors and nurses taking to TikTok, the volunteers knocking down disinfo on social media, and the vaccine research coordinator posting Covid-19 Instagram memes.

At the same time, it's important not to be reductive. The history of the Black community is not only Tuskegee, and it would be unthoughtful to assume that all people from that community react to a politicized, fast-tracked vaccine through that frame. In considering what would cause minority groups to be hesitant about the Covid-19 vaccine, researchers who come from within those communities say that it's equally important to consider what might cause them to accept it.

"How many people of every race and ethnicity are worried about cost, worried about access, worried about whether or not they have health insurance?" asks Jewel Mullen, a physician and the associate dean for health equity at the University of Texas at Austin's Dell Medical School, who is African American. "There are a lot of other considerations that can be in the way of somebody wanting to receive a vaccine."

It's difficult to remember in the rush to get people vaccinated—or what will be a rush, once a vaccine exists—but vaccination is a part of health care, and the most successful health care begins with a conversation: about signs and symptoms, sure, but also about what worries people and what they value. It's still not known, after all, just what the coming vaccine will do: prevent infection, reduce severity of illness, keep people from dying? A person's willingness to take the vaccine might depend on that answer, as much as on their knowledge of history or past experience with other vaccines.

"Perhaps a good message would be: While we understand how important it will be for people to believe in the safety of a vaccine, so that they can decide whether or not they want to receive one, we are equally committed to talking to them about the other issues that might be on their minds," Mullen says. The experience of reaching out to people about Covid-19 vaccines, she adds, should not just be about convincing them. It should be about reminding them that health workers care about their well-being.

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Maryn McKenna (@marynmck) is a contributor for WIRED. She writes about public and global health and food policy, and she is a senior fellow at the Schuster Institute for Investigative Journalism at Brandeis University. She is the author of *Beating Back the Devil*, *Superbug*, and *Big Chicken: The Incredible Story... Read more

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