Understanding the "system distrusters"

The Issue

As COVID-19 vaccination efforts continue in the United States, it is becoming clear that hesitancy cannot be explained reliably by traditional demographic categories (e.g., political affiliation, race, age, gender, economic status). Instead, some distinct personas are emerging based on shared beliefs and barriers to getting the vaccine. These personas both transcend and encompass the traditional demographic categories—each persona includes at least some members of every demographic group.

One of these personas is the "system distrusters." Their hesitancy is related to trust in and access to a health care system that has an inequitable history.

What You Need to Know About System Distrusters

Based on polling and psychobehavioral analysis conducted by Surgo Ventures, approximately 4% of Americans are system distrusters.[1] They are likely, but not exclusively, members of communities of color. Their primary belief is that people of their own race are not treated fairly by the health care system. Negative experiences are common to many people within these groups.

The concerns of system distrusters are best understood by considering the legacy of health care discrimination, medical research exploitation, and unconsented experimentation on Black, Hispanic, American Indian, Alaska Native, and other minority communities. Examples include:

- The U.S. Public Health Service Syphilis Study at Tuskegee, in which hundreds of Black men in Alabama were lied to about being treated for syphilis so researchers could observe the disease running its natural course.
- The Edmonston-Zagreb measles vaccine trial, during which parents of immunized infants (mostly from poor Black and Hispanic families) were not informed that the vaccine used was an unapproved experimental vaccine.
- Instances of unconsented sterilization of Hispanic, American Indian, and Alaska Native women.

In addition, some social determinants of health—the conditions in the places where people live, learn, work, play, and worship—have historically prevented members of racial and ethnic minority groups from having fair opportunities for economic, physical, and emotional health. These health disparities persist today: surveillance data show that the COVID-19 pandemic has disproportionately affected racial and ethnic minority groups in the United States. One recent cohort study found that Black patients hospitalized with COVID-19 had higher rates of hospital mortality or discharge to hospice than White patients after adjustment for the personal characteristics of those patients. Those higher rates were explained by differences in the hospitals to which Black and White patients were admitted.[2]

System distrusters also may be concerned that the COVID-19 vaccines were not tested adequately in "people like them." Racial and ethnic minority populations typically have been underrepresented in clinical trials. As a result, differences in the efficacy and safety of interventions in people of different races and ethnicities sometimes have become apparent only after widespread use.

What Might Work

An important aspect of engaging with system distrusters—as the name of this persona implies—is working to build trust. One strategy is to foster meaningful engagement with community institutions and diverse leaders, with a goal of increasing both confidence in the COVID-19 vaccines and access to them.

The first step is to listen and learn from community concerns. Is it possible that some community members had a negative experience with COVID-19 testing that carried over to vaccination? Do these system distrusters have questions about how the COVID-19 vaccines were tested or concerns about their safety? It may be beneficial to arrange community events where people can ask questions openly and discuss their concerns. Ideally, those events would feature health care professionals and "trusted messengers" (e.g., pastors, teachers) who are members of the specific community, and the event would be as culturally responsive as possible (e.g., sensitive to local language needs).

As shown in Table 1, based on the current representation of racial and ethnic minority groups in the total U.S. population, most racial and ethnic minorities were under-represented in the clinical trials for the three currently authorized COVID-19 vaccines (i.e., Pfizer-BioNTech, Moderna, and Johnson & Johnson/Janssen). However, those clinical trials included a much larger and more diverse number of participants than usual. In total, the Pfizer-BioNTech and Moderna trials enrolled more than 6,000 Black volunteers and more than 10,000 Hispanic volunteers. The trial for the Johnson & Johnson/Janssen vaccine had the most geographically and ethnically diverse population to date. The trials showed that the vaccines were equally effective for all racial and ethnic groups.

Table 1. Race/Ethnicity of Participants in COVID-19 Vaccine Clinical Trials

Population	Representation in U.S. Population[a]	Representation in Clinical Trials		
		Pfizer-BioNTech	Moderna	Johnson & Johnson/Janssen
Total people	**258 million**	**40,277**	**27,817**	**39,321**
Race				
White	73.6%	81.9%	79.4%	62.1%
Black	12.3%	9.8%	9.7%	17.2%
Asian	5.9%	4.4%	4.7%	3.5%
American Indian or Alaska Native	0.8%	0.6%	0.8%	8.3%
Native Hawaiian or Other Pacific Islander	0.2%	0.2%	0.2%	0.3%
Ethnicity				
Hispanic or Latino	17.6%	26.2%	20.0%	45.1%
Not Hispanic or Latino	82.4%	73.2%	79.1%	52.4%

[a] *16 years of age or older.*

American Pharmacists Association. Reach Diverse Communities. Available at: https://vaccineconfident.pharmacist.com/Learn/Build-Vaccine-Confidence-In-Others/Reach-diverse-communities

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Furthermore, some of the COVID-19 vaccine researchers represented diverse backgrounds.

Another important consideration for system distrusters is how easily they can get vaccinated, and how comfortable they might feel doing so. Where are community members most likely or most willing to get vaccinated? What services does the community access frequently that could be used to promote and offer COVID-19 vaccination? Possibilities include local pharmacies, health clinics, recreational centers, grocery stores, food pantries, and places of worship—also nontypical venues such as hair salons or barbershops, Boys and Girls Clubs, or local fire departments. Local employers also might be willing to host vaccination events.

All of the information shared about the COVID-19 vaccines should be clear, transparent, and consistent. Early problems with the vaccine rollout—racial inequity, supply and demand, production issues, etc.—should be acknowledged openly. Be aware that even seemingly innocuous choices, such as which vaccines are being offered to specific communities, could be viewed through a lens of distrust. Finally, be prepared to highlight ongoing efforts to ensure an equitable vaccine rollout and mitigate existing disparities.

References

1. Sgaier SK. Meet the four kinds of people holding us back from full vaccination. *The New York Times*. May 18, 2021. https://www.nytimes.com/interactive/2021/05/18/opinion/covid-19-vaccine-hesitancy.html. Accessed July 28, 2021.
2. Asch DA, Islam MN, Sheils NE, et al. Patient and hospital factors associated with differences in mortality rates among Black and White US Medicare beneficiaries hospitalized with COVID-19 infection. *JAMA Netw Open.* 2021;4(6):e2112842. doi: 10.1001/jamanetworkopen.2021.12842