



Understanding the “System Distrusters”

Note: While this section was written with COVID-19 vaccines in mind, many of the general principles apply to other vaccines as well. Individual vaccines may vary in their antigenic components or dosage forms, but the principles of human behavior and good communication skills transcend most differences between vaccines.

The Issue

When COVID-19 vaccination efforts began in the United States, it became clear that vaccine hesitancy could not be explained reliably by traditional demographic categories (e.g., political affiliation, race, age, gender, economic status). Instead, some distinct personas emerged based on shared beliefs and barriers to getting the vaccine. These personas transcend traditional demographic categories, and each persona includes at least some members of every demographic group.

According to the nonprofit organization Surgo Ventures, one of these personas is the “system distruster.” Hesitancy among system distrusters is related to trust in and access to a health care system with a history of inequities.

What You Need to Know About System Distrusters

Based on polling and psychobehavioral analysis conducted by Surgo Ventures in 2021, approximately 4% of Americans are system distrusters.¹ They are likely, but not exclusively, members of communities of color. Their primary belief is that the health care system does not treat people of their community fairly. 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, where hundreds of Black men in Alabama were lied to about being treated for syphilis so researchers could observe the disease's natural course.
- > During the Edmonston-Zagreb measles vaccine trial, parents of vaccinated infants (mostly from poor Black and Hispanic families) were not informed that the vaccine used in the trial was an unapproved experimental vaccine.
- > Instances of involuntary 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 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 where Black and White patients were admitted.²



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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 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 to increase 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 they carry over to vaccination? Do these system distrusters have questions about how the COVID-19 vaccines were tested or concerns about vaccine 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). Just because someone asks questions does not mean they are against vaccination. They are vaccine contemplators seeking information to help them make their decision.

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%

^a16 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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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 initial clinical trials for COVID-19 vaccines. However, those clinical trials included a much larger and more diverse number of participants than usual. The Pfizer-BioNTech and Moderna trials enrolled more than 6,000 Black and more than 10,000 Hispanic volunteers. The trial for the Johnson & Johnson/Janssen vaccine (no longer distributed in the United States) 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.

Furthermore, some of the COVID-19 vaccine researchers came from 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? Which services and sites could be used to promote and offer COVID-19 vaccination? Possibilities include local pharmacies, health clinics, recreational centers, grocery stores, food pantries, places of worship, 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 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 were or 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. Share evidence-based information and be supportive as individuals contemplate their vaccination decisions.

References

1. Sgaier SK. Meet the four kinds of people holding us back from full vaccination. The New York Times. May 18, 2021. Accessed February 28, 2022. <https://www.nytimes.com/interactive/2021/05/18/opinion/covid-19-vaccine-hesitancy.html>
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

