

# “Do I Have to Be Tested?”: Understanding Reluctance to Be Screened for COVID-19

A 35-year-old recent immigrant from El Salvador calls an immigrant hotline in May 2020, reporting five days of cough, muscle aches, fever, and chills. Coronavirus disease 2019 (COVID-19) testing is ordered. When offered the testing appointment, he declines. The clinician wonders what sort of person would decline COVID-19 testing.

Widespread severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) testing by public health systems is widely acknowledged as necessary. Many communities distrust these systems, however, given their histories of racist treatment<sup>1</sup> and their current roles in perpetuating inequities in health outcomes. Those outcomes are driven by both racial and class inequities beyond public health systems and exacerbated by economic barriers to and discrimination within health care. Racialized inequities are further exacerbated by America's immigration policies and practices. Together, these dynamics explain the disproportionately higher COVID-19 mortality rates in Black and Latinx communities.<sup>2</sup>

To understand and address why members of minority communities might decline testing, then, we must situate the

pandemic and the public health responses to it within both the ethnoracial dynamics of everyday life in America and the racialized state (in)actions in the face of emergencies. The current pandemic is the latest emergency inordinately affecting American communities of color. These emergencies are often described as natural disasters, but their inequitable effects reflect the social organization of “normal” life.

Neighborhoods damaged by Hurricane Katrina, for instance, featured significantly more residents of color and less wealth than did undamaged neighborhoods. This pattern reflected the status quo ante, in which conditions in the former neighborhoods rendered them most susceptible not just to high winds and flooding but also to all the hurricane's sequelae.

This legacy has consequences. Distrust of the state because of racist and classist government (in)actions has been a key reason that some communities have not heeded mandatory evacuation orders<sup>3</sup>—a useful parallel to mandatory pandemic measures such as safer-at-home policies; this must be considered in assessing contradictory data about support for and adherence to COVID-19 response measures, including testing.<sup>4</sup>

Given this combination of experiences within and among American communities of color, an effective and ethically sound mandatory testing program requires addressing the specific barriers that members of these communities are likely to face.

## BARRIERS TO MANDATORY TESTING IN COMMUNITIES

First, a fundamental question: what does mandatory mean? COVID-19 testing is not required by law anywhere in the United States, but most COVID-19 testing reported as voluntary has been required by schools, employers, and institutions for their constituents to return to in-person activities. The return of students and workers to in-person operations at many universities, for example,

is conditional on compliance with testing requirements (e.g., students twice a week; employees once a week). This example highlights challenges of privilege, consent, and coercion for various groups, even absent legal force.

## Financial Barriers

Throughout this pandemic, many in the United States have had to choose between exposing themselves and their families to infection and making a living. Workers at meat-processing plants are a prime example: nearly 200 plants nationwide have reported cases.<sup>5</sup> Workers at many plants are poorly paid and do not receive sick leave. Furthermore, recent government action protects these plants from liability for employee illness. Employees who receive positive test results are thus forced to choose between the “ethically responsible” choice of staying home and the need to earn money to ensure food and shelter.

Mandatory testing, and thus mandatory quarantine for those who test positive, is destined to fail if testing positive augurs financial ruin for large segments of the population. Similar dilemmas confront workers at Amazon, Walmart, and other businesses in

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This editorial was accepted September 4, 2020.  
<https://doi.org/10.2105/AJPH.2020.305964>

which laborers lack workplace protection.

### Immigration Status

Foreign-born individuals constitute a significant percentage of frontline and essential workers. These communities are more vulnerable to SARS-CoV-2, largely because their jobs place them at higher risk for infection (such as restaurant and warehouse work). They are unable to access the social services available to US citizens, which were inadequate even before the pandemic, and are actively discouraged from seeking health care because of the Public Charge Rule, which counts an individual's use of public resources against him or her in immigration hearings. Many undocumented immigrants and foreign-born individuals fear that COVID-19 testing might be used as a pretext to deport them from the United States.

### Fear of Repercussions

COVID-19 testing in procedural or surgical settings is now a near-universal practice; the repercussions of such testing are significant. Many women and their partners fear separation from their infant if their test result is positive, for example, and no standardized guidelines exist on disposition of the neonate from a mother with COVID-19. This is particularly a concern for undocumented immigrants because many fear deportation as a consequence of separation. In addition, no standard protocol has been established for postpartum follow-up, and women with COVID-19 may fear receiving substandard or stigmatized care.

### Stigma and Stereotype Threat

Testing for HIV and other sexually transmitted infections continues to be stigmatized. Similarly, already marginalized communities are further disadvantaged because of their perceived association with SARS-CoV-2. Discrimination and physical violence against Asians, Latinx, Hasidic Jews, African Americans, and others have been amply documented; at both the communal and the individual level, these threats disincentivize participation in testing. Stereotype threat may further disincentivize members of these communities from pursuing testing out of concern that testing positive would confirm prejudices.

### Research Aversion

The history of medical research in the United States is replete with racist violence and exploitation. As a result, distrust of medical research is widespread among Black and other minority communities.<sup>6</sup> COVID-19 testing that occurs in the context of research, including clinical trials, thus will face suspicion from members of communities who have been harmed under the auspices of research for the common good.

### Science, Conspiracy, and Misinformation

The pandemic has intensified preexisting debates about scientific expertise. Public awareness of replication crises, alongside the use of empirically unreliable claims packaged in scientific terminology, methodology, and publication (e.g., the vaccine-autism link), have compounded an underlying mistrust of clinicians, as well as the too-often malignant or negligent relations

between health care institutions and communities of color.

Misinformation and disinformation (e.g., the claim that Black people are immune to COVID-19 and, conversely, that the virus was manufactured to harm communities of color) thus worsen extant estrangement between communities of color and public health institutions and their sets of knowledge sources and practitioners. Furthermore, the sources of misinformation and disinformation are often more trusted than the public health institutions. Those institutions' attempts to condemn or even simply debunk such sources thus are counterproductive.

## ETHICAL IMPLEMENTATION OF COMMUNITY TESTING

Balancing individual interests and the common good is a fundamental ethical challenge for public health. Testing policies that encroach on the autonomy of individual members of vulnerable communities will likely infringe on the rights of the vulnerable while yielding too little test coverage to benefit the population. Testing must be made an attractive option for all through earning community trust. One potential approach, testing and contract tracing as a case-finding method, cannot be implemented in a way that earns such trust if positive results continue to require reporting with full identifiers (e.g., in HIV case finding). By contrast, testing as a surveillance method (anonymous-unlinked) would be less infringing.

Unidirectional messaging campaigns will not solve "poor compliance" with COVID-19 testing or prevention; in fact, they

can further estrange communities that must be enlisted in these efforts.<sup>7</sup> It is unwise to assume that vulnerable communities do not have facts about COVID-19 (or other health issues) and insufficient to ensure simply that they do have those facts, especially when they are excluded from the processes through which these facts are discovered and disseminated. If such communities are to be fully and effectively included in public health efforts, the social and political structures that harm them, and lead to recurring harmful consequences, must be dismantled and remade, with the most-affected communities in the lead. **AJPH**

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All authors conceptualized the argument underlying the editorial. A. Egelko and L. Arnaout wrote the initial draft of the editorial and made final revisions. J. Garoon, C. Streed, and Z. Berger critically read and revised the editorial. Z. Berger supervised the research team.

### CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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