

Structural Transphobia, Homophobia, and Biphobia in Public Health Practice: The Example of COVID-19 Surveillance

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 See also Bowleg and Landers, p. 1604.

Public health surveillance can have profound impacts on the health of populations, with COVID-19 surveillance offering an illuminating example. Surveillance surrounding COVID-19 testing, confirmed cases, and deaths has provided essential information to public health professionals about how to minimize morbidity and mortality.

In the United States, surveillance has also pointed out how populations, on the basis of geography, age, and race and ethnicity, are being impacted disproportionately, allowing targeted intervention and evaluation. However, COVID-19 surveillance has also highlighted how the public health surveillance system fails some communities, including sexual and gender minorities. This failure has come about because of the haphazard and disorganized way disease reporting data are collected, analyzed, and reported in the United States, and the structural homophobia, transphobia, and biphobia acting within these systems.

We provide recommendations for addressing these concerns after examining experiences collecting race data in COVID-19 surveillance and attempts in Pennsylvania and California to incorporate sexual orientation and gender identity variables into their pandemic surveillance efforts. (*Am J Public Health*. 2021;111(9):1620–1626. <https://doi.org/10.2105/AJPH.2021.306277>)

At the time of this writing, after having reviewed publications and public health and press Web sites, and after discussions with experts in the field, we can report that not a single public health surveillance reporting system at any level (e.g., local, state, or federal) in the United States has publicly reported the impact of COVID-19 on sexual or gender minorities (SGMs). This is more than a year since the first-reported COVID-19 case in the United States and despite literature documenting higher rates of COVID-19 risk factors among SGM communities providing a compelling argument that SGM people may be

disproportionately burdened by COVID-19. SGM communities have consequently had to estimate the impact of COVID-19 by extrapolating from data in other studies on the prevalence of underlying risk factors for COVID-19 infection. This extrapolation process, which requires major assumptions, is how SGM communities have had to confront every public health emergency they have faced in the past 50 years.

Of the 10 medical conditions identified by the Centers for Disease Control and Prevention (CDC) as risk factors for severe illness from the virus that causes COVID-19, there is evidence

that lesbian, gay, bisexual, and transgender (LGBT) people are at higher risk than the general population for nearly all of them.¹ These risk factors include smoking; lung, anal, and breast cancer; chronic obstructive pulmonary disease; heart conditions; obesity; type 2 diabetes mellitus; and immunocompromised state.^{2–9} Despite documented higher rates of these risk factors among SGM communities, federal, state, and local agencies in charge of monitoring infectious diseases have almost universally failed to collect the data necessary to determine and lessen the impact of COVID-19 infection in these

communities. Excluding SGM communities from public health data collection has previously been identified as public health malpractice.¹⁰ The spread of COVID-19 in these communities provides a tangible case study of the consequences of this continuing malpractice.

The influence data can have on policies, programs, and funding is evidenced in our response to COVID-19 for populations for which data are available. Race, ethnicity, age, and socioeconomic status have all been shown to be independently and together associated with COVID-19–related infections and deaths.¹¹ While these data are often incomplete, existing data have brought a spotlight on how some populations are differentially impacted and interrelated. However, for SGMs, these data are not just incomplete, they are nonexistent. The need to determine the toll of COVID-19 on SGM communities is pressing, as well as a determination of how these population characteristics interact and compound with each other. For example, Black transgender individuals are almost certainly likely to experience COVID-19 very differently from White cisgender gay, lesbian, and bisexual people because of systemic racism and transphobia.¹

At the beginning of the pandemic, more than 100 lesbian, gay, bisexual, transgender, and queer (LGBTQ) and ally organizations, including the Gay and Lesbian Medical Association, Fenway Health, Whitman Walker Health, SAGE, the New York Transgender Advocacy Group, and the National Queer Asian Pacific Islander Alliance signed an open letter aimed at health professionals and the media highlighting the increased risks of COVID-19 infection in SGMs. The letter writers provided extensive suggestions for community-

based organizations, health care centers, medical professionals, and the media that have not been met, including “Ensuring surveillance efforts capture sexual orientation and gender identity as part of routine demographics.”¹² A second letter was issued in April 2020 with 170 allied organizations urging the collection of sexual orientation and gender identity (SOGI) data, yet SOGI data collection is still barely occurring.¹³

Because SOGI variables are rarely ever included in public health data collection efforts, public health experts investigating the health of these communities are almost always left to make conjectures about diseases such as COVID-19 on the basis of limited information about these communities in other areas of health. The concern expressed in the letter described previously is one such instance in which community members, knowing the risk factors for a new disease, surmised a need to respond.

For example, one risk factor that disproportionately affects SGM communities is smoking. COVID-19 is a respiratory infection, and smoking increases the likelihood of severe COVID-19. Lesbian, gay, and bisexual (LGB) people in the United States are 1.52 times more likely to report current cigarette use than non-LGB people.¹⁴ This not only places LGB persons at elevated risk for severe COVID-19 infection, but also for lung cancer, liver cancer, colorectal cancer, prostate cancer, breast cancer, cardiovascular disease, chronic obstructive pulmonary disease, and type 2 diabetes, which are further risk factors for severe COVID-19 infection.¹⁵ LGBT people also have higher rates of asthma, another respiratory condition that may increase risk of severe COVID-19 infection (21% in

LGBT adults vs 14% in non-LGBT adults).^{16,17}

Very few studies have been conducted on HIV-infected individuals with COVID-19. However, people with HIV infection are more likely to have serious chronic medical issues, including cardiovascular and lung disease, immune suppression, and other chronic conditions that arise with old age.^{18,19} All of these medical conditions place one at higher risk for severe COVID-19 infection. Mirzaei et al. note that while HIV-positive people had similar risk factors to HIV-negative people for COVID-19 infection, severe morbidity and mortality co-occurring in HIV and COVID-19 infection were most affected by the presence of multiple diseases and age.²⁰ A second 2020 study found that severe clinical outcomes were common among patients with HIV diagnosed with COVID-19. Risk for severe COVID-19 infection among HIV-positive individuals was higher for those with comorbidities and low CD4 cell counts¹⁸

In addition to the previously mentioned concerns, sexual minorities are at greater risk for hypertension and cardiovascular disease. A review conducted by Caceres et al. on cardiovascular disease in SGMs found that sexual-minority men and women are at elevated risk for heart disease.⁵ Heart conditions and hypertension are other medical conditions identified by the CDC that lead to increased risk of severe COVID-19 infection.

Furthermore, there are also social determinants and inequities that put SGM people at higher risk for infection and other harms during the COVID-19 pandemic. These social determinants and social inequities faced by SGM people are clear, obvious, and have been well documented for decades. For example, SGMs are health insured at

lower rates than cisgender heterosexual people and have higher poverty rates, and nearly 1 in 10 LGBT individuals are unemployed.^{16,21–23} This results in decreased access to lifesaving care such as HIV medications and gender-confirming surgery for transgender individuals.⁸

Another cause for concern is that 40% of LGBT people work in service jobs as opposed to 22% of cisgender heterosexuals.²³ LGBT persons are more likely to lose their jobs as industries shut down, putting them at greater risk for job insecurity and poverty.⁸ In addition, LGBT individuals that have remained in the workforce during the pandemic are more likely to be in physical contact with people during the pandemic, which places them at higher risk for COVID-19 infection. Furthermore, transphobia, homophobia, and biphobia in the workplace decreases access to social services and fosters an unsupportive environment, which can lead to poor health outcomes.^{8,24}

Social isolation and parental and family rejection are also potential COVID-19 risk factors disproportionately affecting SGMs. These problems can lead to a cascade of negative mental health effects, especially in younger populations and the elderly.^{22,25} Because many schools have closed, SGM youths are forced home to live with often unsupportive families and lose access to various school supports. It has been estimated that one third of LGBT youths experience parental rejection.²³ LGBT youths who are rejected by their families are 8 times more likely to attempt suicide and 6 times more likely to have depression.²³ Parental rejection often forces youths out of their homes, which we see reflected in rates of homelessness, which disproportionately affects SGMs.^{8,25} In addition, LGB adults have 3

times greater risk for opioid use disorder than heterosexual adults.²⁶

Older LGBT individuals are more likely to be single, living alone, and estranged from their biological families. It has been estimated that there are 2.7 million LGBT adults aged older than 50 years in the United States.²⁷ Isolation and lack of familial and social support are all significant burdens facing older LGBT people.²³ In addition, older lesbian, gay, bisexual, transgender, and queer plus (LGBTQ+) individuals are less likely to seek medical attention, are less likely to have a primary care provider, and may fear discrimination from health care providers—all of which present significant barriers to accessing health care.²⁸

It is also important to note the lack of homogeneity among SMG populations to understand how LGBT individuals experience various health outcomes. Not only are cisgender lesbians likely to have different health experiences than transgender lesbians, but there will also be differences across other characteristics such as race and ethnicity. For example, gay and bisexual men are the population most heavily impacted by HIV and made up 69% of new HIV infections in 2018.⁶ When broken down by race/ethnicity, Black/African American gay and bisexual men made up 37% of new diagnosis, followed by Hispanic/Latino gay and bisexual men at 30%, followed by White gay and bisexual men at 27%. Having all of the aforementioned variables would illuminate COVID-19–related health disparities by SGM status and race and ethnicity.

We could easily expand upon this brief review of risk factors for contracting COVID-19 and for worse outcomes resulting from COVID-19 infections in SGMs, but the indirect evidence presented here should engender

tremendous concern among all public health professionals. It certainly has incited intense concern among public health professionals who focus on the health of SGMs, as well as within these communities.

Unfortunately, as is most often the case for investigating the health of SGMs, in this review, we have had to rely on indirect data and deductive reasoning to understand an emerging health concern. But deductive reasoning only gives us a blurry window into actual concerns and needs. We are left wondering, once again, how our response to an epic public health tragedy would have played out if better data were available. The absence of SOGI variables in public health surveillance systems is public health malpractice that was predicted and should have been averted.

COVID-19 SURVEILLANCE IN THE UNITED STATES

Summarizing the current COVID-19 data collection and surveillance system is no easy task. The public health surveillance system in the United States was constructed in a piecemeal manner over the past century as technology, culture, and public health needs shifted, resulting in multiple data collection channels and reporting pathways. While case and mortality data for COVID-19 are reported to the CDC through separate surveillance systems (National Notifiable Disease Surveillance System and the National Vital Statistics System, respectively), laboratories are required to report data to the Department of Health and Human Services (HHS).^{29,30} Although data can be submitted directly to HHS, data can also be sent to state health departments or officials first, adding a second step. Data can also be

submitted through Teletracking, a patient flow automation system.³¹ Clearly, the current system allows substantial room for error, being decentralized across 50 states and territories, and with no centralized data collection pathway. Other limitations include incomplete case reporting data, incomplete laboratory data streams with diagnostic data compiled from a variety of sources, and critical information missing in mortality data, including race and ethnicity data.³⁰

THE EXAMPLE OF RACE AND ETHNICITY DATA

Previous research on health inequities for Black Americans and other race and ethnicity groups in the United States combined with data on race and ethnicity reported during the COVID-19 pandemic has led researchers and academics to conclude that Black Americans in particular are at higher risk for COVID-19 infection and death because of factors such as racism, housing inequities (i.e., crowding housing conditions where people cannot socially distance), lack of access to health care, and higher rates of employment in the service industry. Given past atrocities perpetrated by some within the medical community and the current negative effects of systemic racism on Black health, it is imperative that the medical community earn the trust of Black Americans seeking care and continue education and outreach. The COVID-19 vaccination campaign provides an opportune moment to do so. For example, concordant messaging from Black doctors increases information-seeking behavior among Black communities.³² As a result of these findings, research has been conducted to increase our knowledge of COVID-19

infection in Black Americans in the United States, and there are health and policy recommendations to reduce COVID-19 infection in this population, as well as efforts to foster education and provide resources at the local and the national level among the Black population.^{33,34} Ethnicity is another important social determinant of health, as Hispanic/Latinx individuals in the United States are hospitalized at more than 3 times the rate as White individuals for COVID-19 infection and experience an infection rate that is 1.3 times higher. This is of concern given the growing Hispanic/Latinx population in the United States.

The guidance, policies, and laws that dictate the collection of race and ethnicity data in existing systems are helpful models for understanding how SOGI data can also be collected and reported. Numerous guidelines pertain to the collection of race data in public health surveillance with the most recent, in relationship to COVID-19, being issued on June 4, 2020. This guidance requires the collection of demographic data including race “to ensure that all groups have equitable access to testing, and allow us to accurately determine the burden of infection on vulnerable groups.”³⁵

Despite guidance and years of efforts to include valid and reliable measures of race and ethnicity in surveillance data, the systems used to monitor disease in the United States are failing. As has been historically the case with the reporting of other diseases, race data are frequently missing, and, when collected, they are not collected in standard categories or using methods that have been evaluated to minimize error. Krieger et al. reported that data on race were missing for 50% of individuals included in the CDC COVID Data

Tracker as of September 16, 2020.³⁶ Reporting of race data has only improved slightly in the 5 months since then, with 48% of cases missing race/ethnicity data at the beginning of March 2021. Furthermore, data reporting from The COVID Tracking Project indicates that some of the states with the most missing data might have higher concentrations of racial and ethnic minorities, indicating that the impact of COVID-19 in Black communities might be underestimated.³⁷

It is imperative to examine effects of COVID-19 for those marginalized by race in addition to their SGM status, as there is evidence that individuals with double or triple minority status experience disproportionate morbidity. Data from The Williams Institute at the University of California, Los Angeles found that LGBT people of color are twice as likely as White LGBT individuals to test positive for COVID-19, highlighting the increased risk for those who live at the intersection of racial minority and SGM status.³⁸ In addition, the CDC’s *Morbidity and Mortality Weekly Report* published an analysis on COVID-19 in February of 2021 on outcomes for SGM by race/ethnicity. The authors concluded that risk for COVID-19 may be magnified for non-White SGMs. Furthermore, they acknowledged that the data are not being collected, and emphasized the need for intersectional SGM data to improve health equity.¹

INADEQUATE PROGRESS IN DATA COLLECTION

Because years of systemic discrimination and oppression in the United States are reflected in our health care and medical system, there are currently no data being collected on COVID-19

testing, infection rates, or deaths among SGMs, with the exception of Pennsylvania, California, District of Columbia, and Illinois, whose efforts have not yielded publicly reported findings at the time of this writing. More than 500 000 people have died from COVID-19 infection to date, yet we have no information regarding how many of them were SGM individuals.¹¹ The federal government's lack of initiative and action in regard to collecting SGM data in COVID-19-infected patients as well as through contact tracing demonstrates negligence given the concerns described previously.

Only Pennsylvania, California, Illinois, and the District of Columbia have made attempts to collect SOGI data in any part of their COVID-19 surveillance systems. The Illinois Behavioral Risk Factor Surveillance System survey had existing questions on SOGI, and, in 2020, a module on COVID-19 was added. While the District of Columbia is said to be collecting SOGI data, there is little evidence of this, and no data are available.¹ These limited attempts provide models that can be evaluated and potentially used elsewhere.

Pennsylvania initiated a systematic data collection process through governor Tom Wolf's orders. The state acted swiftly and announced the data collection program on March 13, 2020.³⁹ The Pennsylvania Department of Health, which uses Sara Alert for case surveillance, case investigation, and contract tracing, has been modified to include questions on SOGI.⁴⁰ In addition, the Pennsylvania Department of Health requested that the eHealth Authority Board of Pennsylvania require the state's 6 health information centers to gather data on SOGI by using electronic medical records. We could not find any publicly reported results from these

data collection efforts. Nonetheless, Pennsylvania's commitment and eventual success in gathering SOGI data should be evaluated as a possible model for other states.

In California, we see a second strategy—the introduction of SOGI data collection through state-level legislation. California Governor Gavin Newsom signed Senate Bill 932 on September 26, 2020. The bill requires an option to collect data on sexual orientation and gender minority status when gathering data and reporting cases of communicable diseases, including COVID-19.⁴¹ This is an important success as California is the first state to pass a law that requires SGM data collection for all communicable diseases. Still, there are major concerns with waiting for legislation to be passed to address SOGI data collection.

In addition, in July of 2020, Health and Human Services of California set forth emergency legislation that required local health departments and providers to collect SOGI data given voluntarily to understand the effects of COVID-19 on SGM populations.¹

California State Senator Scott Weiner expressed his frustrations with needing legislation in California to start SOGI data collection saying:

I wish I had not been forced to introduce this legislation.... I usually don't say that. This is frankly an issue that should've been taken care of already.... Frankly, even without the law, or a law, the State of California and our counties, and our healthcare providers should already be collecting this data.⁴²

Senator Weiner brings up 2 key points: (1) the importance of collecting SGM data has been made clear by empirical evidence and human rights organizations, and it should be a given

that these data would be collected during the COVID-19 pandemic, and (2) that there can and should be local efforts in a state to collect SOGI data even when we do not see movement at the state or federal level. Unfortunately, despite clear need for SOGI data, New York, California, Oregon, New Jersey, and the District of Columbia are the only places where SOGI data collection is mandated for any purpose other than hate crimes.^{1,43} Weiner also commented that there is also no data collection around hospitalization and death rates for LGBT people. Furthermore, he concluded that SGMs are often an afterthought even though we have the means and resources to collect these important data.⁴²

We note here that executive orders (as in Pennsylvania) and legislation (as in California) are only the first step toward data collection. The process of implementing questions on sexuality and gender, training health professionals, and monitoring data for accuracy and quality is not an insignificant undertaking as is evidenced in the collection of race and ethnicity data which has not fulfilled existing recommendations.

RECOMMENDATIONS

The public health surveillance system's noncollection of SOGI data is public health malpractice and also evidence of structural homophobia, biphobia, and transphobia. These concerns were identified long before the emergence of COVID-19, which emphasizes the harmful impact these problems can have on SGM communities when not addressed or even publicly recognized by the people and agencies that control public health surveillance systems.

There are not easy fixes to these problems because the system itself is broken, as evidenced by the haphazard and incomplete collection of race data. However, steps must be taken to begin recognizing the concerns of SGMs. While we recommend that the CDC and other public health surveillance experts begin to think about modern ways to overhaul the systems that are failing so many marginalized communities, steps can be taken within the confines of the existing system to right some historic wrongs.

First, we recommend that HHS and CDC issue guidance about the collection of SOGI data like their guidance on race and ethnicity data in relationship to COVID-19. We also recommend that research be funded to further the development of valid and reliable measures of sexual orientation identity and gender identity, as well as pilot studies testing the collection of these data in surveillance systems that can eventually be scaled up to the federal level. In the meantime, states, like Pennsylvania and California, can take the lead by implementing SOGI data collection efforts, and consequently serve as examples for other states and the federal government as they develop models to ensure the next public health emergency fully addresses the concerns of SGM populations otherwise overlooked. *AJPH* *AJPH*

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The authors have no conflicts of interest.

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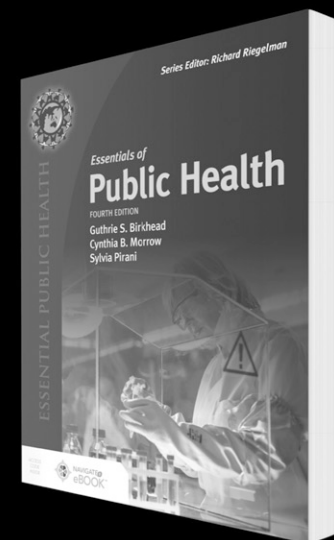
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