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## **Glaring COVID-19 data omission demands a fix**

The Provincetown cluster has reinforced the LGBTQ community's demand that DPH start counting them.

### **By The Editorial Board**

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An indoor mask mandate has been issued in Provincetown after a recent rise in COVID cases following July Fourth weekend celebrations.

The virus doesn't discriminate.

Throughout the past 18 grueling months, those words have become something of a mantra — certainly for health care professionals. It has helped guide testing and vaccination outreach efforts — certainly those made to Black and Latinx communities.

The collection of data by race, ethnicity, disability, and even by profession was deemed so important in fighting the disease that Massachusetts passed [emergency legislation](#) more than a year ago to mandate its gathering and its distribution.

Data remain a critical part of the COVID-19-fighting toolkit. Which is why today there is renewed anger in the LGBTQ community for their conspicuous absence from any COVID-related data collection on sexual orientation or gender identity.

“That data would allow us to understand the effects of COVID and the prevalence of COVID on a population we know to be vulnerable,” said Sean Cahill, director of Health Policy Research at The Fenway Institute at Fenway Health, in an interview. “Without that data, we're operating in the dark, and that's both frustrating and unnecessary.”

Cahill pleaded for such data collection in a [Globe op-ed](#) much earlier in the pandemic.

Today that unheeded plea has become even more relevant in the wake of the COVID cluster traced to July Fourth weekend celebrations in Provincetown — a [cluster that has risen to around 900 infections](#), about three-quarters of them among vaccinated individuals.

“If we had collected data showing, say, that gay men are 20 percent more likely than straight men to get infected, we could have gotten the word out,” Cahill added. “We know how to do this. We've had 40 years of experience fighting AIDS.”

And long before the Provincetown outbreak, there was a body of evidence, [confirmed by the Centers for Disease Control and Prevention](#), that members of the LGBTQ community had

higher rates of diabetes, asthma, heart disease, hypertension, and stroke than heterosexual adults — all conditions that would leave them more vulnerable to COVID infections. So too are those living with HIV and AIDS.

But only [five states](#) — [California](#), Pennsylvania, Oregon, Nevada, and Rhode Island — and Washington, D.C., currently collect COVID data that include sexual orientation and gender identity. Public health officials in Massachusetts have, according to Cahill, had discussions with members of the gay community on the issue more than a year ago, but without any resolution. A department spokesperson said the agency “has continued to regularly review and adjust its reporting to improve metrics.” But that still doesn’t include sexual orientation or gender identity.

The [Health Equity Task Force](#), created by the Legislature more than a year ago, reported its findings July 1. It put “the need for complete and actionable data” as a “guiding principle” in the future fight against COVID and a critical part of the equitable delivery of services.

“This data must be stratified (and disaggregated) by race, ethnicity, language, ability, sexual orientation, gender identity, age, and geographic location. . . . The data must be relevant, transparent, and available to the public, in order to be a driver of change. As someone else said, ‘you can’t change what you can’t measure.’ ”

Precisely. And there is also a broader issue at stake.

“The reason we need to do data-driven, culturally responsive outreach is that medical mistrust — and along with that, vaccine hesitancy — among LGBTQ people is rooted in the stigma and discrimination that this community has experienced over time,” Alex Keuroghlian, a psychiatrist and director of the National LGBTQIA+ Health Education Center and the Massachusetts General Hospital Psychiatry Gender Identity Program, told [The New York Times](#).

Rather than being viewed as intrusive, questions about sexual orientation or gender identity are a way of signaling inclusion.

“Besides, these questions are voluntary,” Cahill said. “You can choose not to answer.”

But because of negative experiences in the past, Cahill agreed that “many gay people may be disproportionately distrustful of the health care community and may be less likely to get tested or to get vaccinated.”

The pandemic has exposed a host of vulnerabilities in minority communities of all kinds. But exposing a problem is the essential first step on the road to solving it.

Asking the right questions in the right way builds trust. It also sheds a bright light on where health care fixes need to be made. This pandemic isn’t through with us yet. It’s not too late to correct this glaring omission.

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