OHSU's virus study accused of racial bias

By ERIN ROSS
Oregon Public Broadcasting

Complaints of racial bias have emerged in a coronavirus study.

Charges of racial bias in the design of an Oregon study of COVID-19's spread are raising questions about whether it will do anything to help black and Latino communities, which have been among those hardest hit by the pandemic.

"All it will be able to say is if white people are fine. And then we open up counties and people of color will die," said Andres Lopez, research director for the Coalition of Communities of Color, a Portland-based alliance of organizations representing a number of different communities of color.

The Key to Oregon study, which plans to enlist 100,000 Oregonians and monitor them for a year for COVID-19 symptoms, will include what its designers are calling "a focus on enrolling people who fully represent the state, including our diversity in geography, socioeconomic status and communities of color."

Because of the pandemic, researchers put the study together in just three weeks.

The goal of the study is to track the spread of the virus and catch outbreaks before they become uncontrollable.

But critics doubt Key to Oregon will succeed in its goal. They say the study design is fundamentally flawed, and that those flaws could have been avoided if people of color had been brought to the table when the study was being created.

"One thing that I want to make very clear is, these are not just my words and ideas," Lopez said. "This is coming from various people of color, represented by grassroots organizations, coalitions, universities, community-based organizations and leaders of communities of color."

When Tyler TerMeer first heard about the project's design, he was skeptical. TerMeer has spent his career in HIV advocacy, and is the CEO of Cascade AIDS and Prism Health. He and other organizers quickly drafted a letter, listing concerns with the study and asking what Oregon Health & Science University planned to do to address them. "We wanted to know how the study would help mitigate mistrust, and how people of color were being involved in the study."

Lopez wrote a letter, too. "I wrote them saying, 'I looked at the proposed study, I looked at the principal investigators, and I don't understand how this will be equitable. There's no talk about community engagement. No talk about funds going to communities. All the researchers on the project are white, and they don't use any type of equitable lens in their research."

Listening sessions

In response to rising criticism of the study's design, OHSU hosted a series of listening sessions and invited community leaders to participate. So far, it's hosted 11 sessions and plans to have more. The study's researchers tell Oregon Public Broadcasting they're planning to use feedback from those sessions to make improvements, so it better captures data on COVID-19's impact on communities of color — but no such adjustments have been made so far.

The study's principal investigator, Jackilen Shannon, said steps were made in the study's design to make sure the participants represent the population of Oregon. For example, researchers plan to oversample in rural areas and in communities of color that have been hardest hit by the virus.

"If we just randomly sampled everybody, we'd probably only end up with one or two people in rural areas or from underrepresented minorities. So to try to account for that, we're taking into account population density and racial demographics," Shannon said.

Any COVID-19 survey that fails to include large numbers of people of color will also fail to inform equitable decisions around health policy and the distribution of medical resources. In large part that's because nationally, black people are dying of COVID-19 at rates much higher than the general population. And in Oregon and other states, Latino people have been disproportionately hit by the virus.

Numerous studies have documented ways that racial biases have created disparities in how people of color access and receive medical care. Health care disparities and other types of systemic racism make black and Latino people more likely to develop preexisting conditions that put them at risk from COVID-19. If they haven't been diagnosed, many may not know they're at risk.

People of color are also more likely to work in jobs that are high risk and considered essential. In the Northwest, COVID-19 outbreaks have been traced back to food processing or packaging facilities, places that are often primarily staffed by immigrants. Lopez said design flaws in public health studies commonly suppress black and Latino voices and result in insufficient data from their communities. And he's worried the Key to Oregon study will do the same.

For example, researchers started to recruit people by first sending out postcards notifying residents about the study. They plan to follow up with a written invitation to participate.

Advocates say that's one of the study's baked-in flaws.

"Using mail to communicate with people in and of itself is problematic," said Dr. Jill Ginsberg, medical director of NxNE, a health clinic serving Portland's black communities. Minorities might live in group-living situations or lack a mailing address. Even if mailers are bilingual, advocates are concerned that people will still face language barriers when it comes to accessing information and being informed before consenting to the study.

Ginsberg is also worried that the racial data OHSU is using to identify areas with large communities of color will be outdated in rapidly-gentrifying urban areas like Portland.

"Targeting the 97211 zip code where our clinic is located might have worked 10 years ago," said Ginsberg, "But today that's not going to be the case."

Shannon said data for the study comes primarily from the 2010 U.S. Census, but it includes more recent data on where people of color live, too. And if researchers don't get enough people of color responding, they plan to send out more mailers and try to recruit another round.

Oversampling

But critics say that even if OHSU successfully targets communities of color, just oversampling isn't enough.

Studies that rely on oversampling "center whiteness and racist methodologies," Lopez said.

He raised the example of a nationwide telephone study conducted by the federal Centers for Disease Control and Prevention, which tracks chronic health conditions across the country. It has historically undersampled minority groups in many states. In 2017, when researchers realized indigenous communities were largely missed by the survey, they tried to recruit more heavily from regions with large indigenous populations.

The Key to Oregon study is trying to do the same, taking up a retrofit solution by over-recruiting from diverse zip codes.

"But it doesn't work," Lopez said. "It fails. They continue to fail. And there's years and years of data and research on why they fail." Lopez said there's no reason Key to Oregon should be any different.

There are several reasons that oversampling strategy doesn't work. The biggest one is trust.

People of color, and black people in particular, have good reason to distrust the government and medical establishment, said TerMeer, who is deeply familiar with the history of racism in medicine.

"There's a long history of experiments being done on black people without their consent, of data being taken and nothing coming back to the community," TerMeer said.

One of the more notorious examples is the Tuskegee study, in which black men seeking treatment in Alabama for syphilis and other conditions were lied to and given sham treatments so the untreated diseases could be studied.

Earlier, J. Marion Sims, the so-called "father of gynecology," developed life-saving treatments in the 1840s by performing painful surgeries without anesthesia on enslaved women.

"Being asked to self-monitor and then report to a government agency might feel very comfortable for someone like me, a white person who works in health care," Ginsberg said. "As a white person, I have an inherent trust in the government. But that's because of my white privilege."

Without the front-end involvement of diverse community organizations, TerMeer said, that distrust will not be overcome.

"I come from HIV advocacy and we have a phrase, 'Nothing about us without us," he said. But because people of color's voices weren't included from the start, OHSU has already made decisions that have set it up to fail, he said.

If OHSU hoped to assuage concerns with their listening sessions, critics said, the researchers were not successful.

Ginsberg, TerMeer and Lopez said those sessions went about the way they expected it to.

"It's very typical of white people in power to make decisions about what they're going to do and how they're going to do it. And then they reach out to extract whatever data or information they can from people of color so they can say that there's some kind of equitable lens or strategy in place," Lopez said.

Virus outbreak hits Pacific Seafood in Newport

By NOELLE CROMBIE
The Oregonian

Pacific Seafood on Sunday disclosed that 124 of its employees and local contractors have tested positive for the coronavirus in what is the second largest workplace outbreak of the virus in Oregon to date.

The number reported by the business is nearly twice what the Oregon Health Authority initially reported Sunday morning. An Oregon Health Authority spokesman said the state pulls the data once a day and that the number of confirmed positives had risen since it collected the data early Sunday.

The public health investigation into the outbreak began June 2, according to the state. State officials said the initial tally fell below the threshold for public disclosure, which the state set at more than five cases in workplaces with more than 30 workers.

Officials said the risk to the public is low.

On Sunday, Pacific Seafood issued a statement saying it provided testing for 376 workers at its five Newport facilities.

Fifty-three employees and 71 local contractors tested positive.

The company said 95% of those who tested positive did not report any symptoms. None have been hospitalized. The positive tests are concentrated at the Pacific shrimp processing facility location.

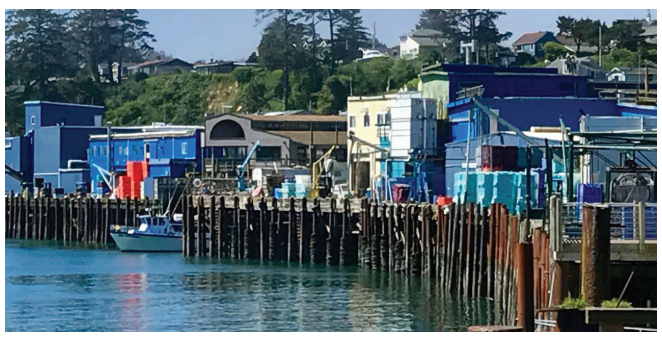
The company said it has suspended operations at all five locations. It also said it would carry out "detailed contract tracing."

An outbreak at Pacific Seafood in Warrenton in May led to 15 cases of the virus.

Meanwhile, a dozen new cases in Hood River that were disclosed Sunday are linked to outbreaks at seasonal agricultural facilities.

According to the latest data from the Oregon Health Authority, the Oregon State Penitentiary in Salem is the largest workplace outbreak in Oregon with 167 confirmed cases. Townsend Farms in Fairview is now the third largest workplace outbreak with a 51 cases.

The disclosures of outbreaks at various businesses came as the health authority reported the highest number of confirmed and presumptive COVID-19 cases to date. The state on Sunday reported 146 new cases and one new death. The second-highest number disclosed on a single day was 100 cases on April 4.



Jeff Manning/The Oregonian

Pacific Seafood in Newport has had a coronavirus outbreak.