Medical Xpress

The full picture: Why we need more demographic data on COVID-19

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Ninez Ponce, director of the UCLA Center for Health Policy Research. Credit: University of California, Los Angeles

By now, we're all familiar with the immense strain the COVID-19 pandemic has placed on our health care system, with many medical

facilities across the country overburdened by high demand and limited supply as they attempt to deal with an influx of affected patients.

But the crisis has also highlighted other health care challenges, including those related to health equity and the striking disparity in risk and outcomes among racial and ethnic groups. Current data show, for instance, that African Americans and Latinos are much more likely than others to be infected and die from the disease. Still, demographic information remains sparse, especially for groups like Asians, Native Hawaiians and Pacific Islanders, and American Indians and Alaska Natives.

Ninez Ponce, director of the UCLA Center for Health Policy Research and a professor of health policy and management at the UCLA Fielding School of Public Health, is working to address these concerns. She spoke to us about the need to collect data on underrepresented groups, what this means for navigating COVID-19 and future public health crises, and how a new tool developed by the center can help policymakers, journalists and others better understand the pandemic.

How is the COVID-19 pandemic shedding light on the nation's health care system?

In a pandemic, we're all at risk, and timely access to health care is crucial in order to diagnose, control and treat patients affected by the disease. Like other public health crises, this one is testing the ability of our health care system to handle the heightened demand for services.

I would say our challenges fall into three broad categories: the availability of care, issues of cost and insurance, and cultural issues that affect those seeking care.

There is a mixture of private and public health insurance coverage in the U.S., and research has consistently shown that cost is a barrier in seeking health care services. It's important to keep in mind that there are still nearly 28 million Americans and 3 million Californians who have no health insurance at all, as well as large numbers of underinsured people.

In fact, when the UCLA Center for Health Policy Research conducted its annual California Health Interview Survey in 2018, nearly 45% of Californians said they had delayed receiving medical care due to the cost or because of a lack of insurance. That's nearly half the population. So people are understandably worried about out-of-pocket costs for testing and treatment.

Other barriers to access include a lack of trust in the health care community among certain segments of the population and a lack of culturally competent care—that is, health care providers who understand the cultural influences of different racial, ethnic or socioeconomic groups and are able to provide health care in a way that is sensitive to those influences. This is especially important because racial and ethnic minorities are poised to become a majority in the U.S. in the next few decades. Researchers and medical professionals have called for greater cultural competency as the nation gets increasingly diverse.

This crisis is illuminating all of these public health barriers, as well as the system's inability to respond to the needs of everyone who is impacted, since COVID-19 affects individuals from all socioeconomic backgrounds, ages, races and ethnicities.

Which groups have been most affected by COVID-19 and why?

Recent reports by the Centers for Disease Control and Prevention and

other health agencies show that black and Latinx groups are being disproportionately impacted by the disease. Black Americans, in fact, are becoming infected with COVID-19 and dying from it at a far higher rate than any other group in America. The reasons for this are not completely clear, but we do know that black Americans suffer disproportionately from certain underlying health conditions like diabetes, high blood pressure and obesity that have been linked to a higher risk of death from COVID-19. A lack of trust in the health care system and lack of insurance may also be contributing factors.

And Latinos fall behind other racial and ethnic groups in coverage and access to health care, which may contribute to poorer health outcomes.

Good demographic information is the key to understanding how and why different groups are affected by the coronavirus, but so far, data are sparse and are especially lacking for such racial and ethnic groups as Asians, Native Hawaiians and Pacific Islanders, and American Indians and Alaska Natives.

For example, California data suggest a disproportionate burden in COVID-19 infections and deaths for Native Hawaiians and Pacific Islanders, but the data are reported only for single-race, non-Latinx Native Hawaiians and Pacific Islanders, even though more than half of this group are multiracial. In the U.S., 62% of American Indians and Alaska Natives are either multiracial or Latinx, and the risk to this community may be hidden if their cases are reported under the multiracial or Latino category.

There are also concerns in the Filipino community, particularly regarding risks to Filipino health care workers. In California, 1 in every 5 nurses is Filipino. Yet the COVID-19 risks are masked for this group because racial statistics include them within the aggregate Asian category.

Generally, there is a paucity of data for these groups and others across the research, and the way that data are broken up do not accurately reflect the picture of what is going on as far as cases and death rates.

Immigrant groups are also at risk, particularly with the current "public charge" legislation, which makes immigrants who receive public benefits like food stamps, housing assistance and, importantly, Medicare ineligible for visas and green cards. This has created a reluctance among these communities to seek public services like health care. The COVID-19 situation is exacerbating these fears and can ultimately lead to worse health outcomes for immigrants as well.

Why is collecting data on additional racial and ethnic groups important?

More data across the nation's diverse mix of racial and ethnic groups translates into greater representation and fairness. This is why I lead the California Health Interview Survey with a health equity–centered framework. The survey collects and reports disaggregated racial and ethnic data on Californians beyond the major racial and ethnic groups—it includes Latinx, white, black, Asian, American Indian and Alaska Native, Hawaiian Native and Pacific Islander, and others—and does so in English and six other languages.

Our approach essentially means that researchers and other health care experts looking at this disease can obtain a more accurate picture of what is really going on and why these differences in health care access and outcomes are occurring.

For COVID-19, policymakers have just passed legislation to support demographic data collection efforts during this unprecedented time. It's imperative that these data are available to ensure that this pandemic does

not further widen the existing health gaps. Data help to identify and address disparities in our health care system that should not go unnoticed.

The UCLA Center for Health Policy Research has created a new tool for examining the COVID-19 pandemic. What is it and how can it be used?

The tool is a dashboard called COVID-19 Rates and Risk Factors by California County and is presented by the center's California Health Interview Survey, or CHIS. It shows various factors cited by health care experts that may be related to COVID-19 cases and deaths—such as underlying chronic conditions and food insecurity.

The data are derived from CHIS, as well as the American Community Survey and the California Department of Public Health. It is publicly available and should be used by researchers, journalists and any individuals who simply want to look at possible factors related to the incidence of COVID-19 in a given community.

The information can also be used by people to advocate for more resources for their counties, and it's important data for legislators to better understand their communities to make more informed decisions.

Provided by University of California, Los Angeles

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