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## In California, efforts to reduce health disparities raise privacy concerns

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California's health insurance exchange wants to collect and use data on a raft of sensitive customer information, from race and ethnicity to sexual orientation and gender identity.

How officials will tackle the task without running afoul of privacy laws remains an open question. A policy on collecting demographic characteristics – potentially far more than currently reported in doctor's offices and passed along to the government – has yet to be developed.

But the goal, foreshadowed in contracts between Covered California and 11 participating insurance companies, is "health equity" – reducing the increased burdens of illness experienced by select populations relative to others.

Exchange officials want to make sure that one racial group doesn't have a higher rate of infant mortality than another, for example, or that women don't die disproportionately of certain illnesses.

"We will be a results-driven organization, including looking at how we are promoting better health and health equity while lowering costs for all Californians," Covered California Executive Director Peter Lee said in a board meeting on the topic earlier this year.

Security of personal information, however, has already been a flashpoint for critics of the federal health care law.

Despite the Obama administration's efforts to assure customers about security, Republicans seized on an early data breach in Minnesota as evidence of the government's inability to safeguard sensitive information such as Social Security numbers, birth dates and income statements.

The collection of demographic data puts the state exchange on a path to "a place that they definitely should not be going," said Sally Pipes, president of the Pacific Research Institute. She said the task of data collection and analysis should be left to research institutions, and worries that even anonymous information on individuals could be identified and misused.

"The more information people have to give out, the more room there is for fraudulent activity," she said, pivoting to the botched launch of the federal health care website. "I think people are becoming skeptical enough about all these things."

Consumers should be able to have the utmost confidence that their personal, financial and health information is secure, said Emily Rusch, state director for the California Public Interest Research Group. But demographic information will help hold the state exchange accountable for doing adequate outreach to

diverse communities, Rusch said.

“We support the sharing of this information if and only if this information is aggregated and de-identified when the insurers provide it to the exchange, so that individual consumer information is kept confidential,” she said.

The federal health care law broadly requires government to report on health care disparities.

Covered California structured its contract in a way that the agency says allows it to obtain protected information from insurance companies without violating another federal law governing privacy of health information, the Health Insurance Portability and Accountability Act.

A previous version of the model contract indicates that the exchange initially was after more information than currently contemplated and on a more frequent basis.

It would have required insurers to submit all claims – covering everything from medical procedures to prescribed drugs – on a quarterly basis to the exchange or a designated recipient. By 2015, it wanted claims broken down by race, ethnicity, gender, primary language, disability status and sexual orientation.

Today, representatives for health insurers and privacy advocates say they don't expect information that identifies individuals to be submitted. The contract now says insurers agree to work with the exchange “to determine how data can best be collected and used to support improving health equity” across race, ethnicity, gender, primary language, disability status, sexual orientation and gender identity.

Stephen Shivinsky, a spokesman for Blue Shield of California, said in a statement that the company would not release enrollee-specific confidential personal or health information unless the exchange can demonstrate it is lawful to do so.

Kaiser Permanente has not yet had detailed conversations with the exchange on providing data, but whatever it shares will be stripped of identifying information and comply with all federal and state laws, spokesman Christian Stenrud said.

The HMO giant frequently provides “de-identified” information on racial and ethnic disparities to researchers, customers, governments and other institutions interested in tracking and eliminating the problem in health care, Stenrud said.

Insurers say they are willing to work on health equity, but want financial incentives to do so.

“Data collection is only the first step,” Stenrud said in a statement. “If we want to eliminate health disparities, health care payers like Covered California should reward health plans and delivery systems when they can show superior, or greatly improved, performance for populations that have historically shown poor health outcomes.”

Ellen Wu, executive director of the California Pan-Ethnic Health Network, said health plans are sitting on a mountain of data. Why not look at who among their customers has diabetes, for example, and target interventions to them, Wu asked.

“The general sense is absolutely we have to treat this data appropriately,” Wu said. “It must be confidential and have the right protections, but it's also important that it's shared and analyzed. One is not exclusive of the other.”

Her organization has been at the forefront of efforts to collect more data. A decade ago, it backed successful state legislation requiring private health plans to assess the needs of enrollees by race, ethnicity and language and provide translation and interpretation for medical services.

Earlier this year, it sponsored a bill that would have required the Medi-Cal program to begin analyzing and reporting quality data by enrollee demographics such as race, ethnicity, primary language, sexual orientation and gender identity.

Gov. Jerry Brown vetoed the measure, saying in the accompanying message that the state can already procure the data if it “sees a need or benefit that justifies the costs.”

The Pan-Ethnic Health Network and other groups have continued to push the issue with the exchange, where reducing health disparities was the topic of a panel discussion earlier this year.

Advocates say the data eventually should be used to boost funding for their constituencies.

Darcel Lee, executive director at California Black Health Network, told exchange board members that while African Americans account for a small percentage of the state population, they carry among the greatest burdens of disease and negative health outcomes.

“If disparities exist between populations, but resources are deployed evenly across the board, you may actually increase disparities because those resources are not getting to the areas where the burden of disease is the greatest,” she said.

The Obama administration, meanwhile, two years ago began pushing to include data aimed at improving the health of lesbian, gay, bisexual and transgender individuals.

Poshi Mikalson, director of the LGBTQ Reducing Disparities Project, said it’s necessary to “call out” sexual orientation and gender identity for the same reasons health experts focus on race, ethnicity and language. She said that doesn’t guarantee that everyone will answer every question.

But Mikalson, who is also the LGBTQ mental health project manager at Mental Health America of Northern California, said the more a question comes up the more normal it becomes.

“People who aren’t counted do not count,” she said.

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