TuSalud

FDA Head Robert Califf Battles Misinformation—Sometimes With Fuzzy Facts

Americans' choices, often informed by bad or misleading data, are among the causes of poor health.

August 9, 2023 By Darius Tahir and KFF Health News

Robert Califf, the head of the Food and Drug Administration, doesn't seem to be having fun on the job.

"I would describe this year as hand-to-hand combat. Really, every day," he said at an academic conference at Stanford in April. It's a sentiment the FDA commissioner has expressed often.

What's been getting Califf's goat? Misinformation, which gets part of the blame for Americans' stagnating life expectancy. To Califf, the country that invents many of the most advanced drugs and devices is terrible at using those technologies well. And one reason for that is Americans' misinformed choices, he has suggested. Many don't use statins, vaccines, or COVID-19 therapies. Many choose to smoke cigarettes and eat the wrong food.

Califf and the FDA are fighting misinformation head-on. "The misinformation machine is really causing a lot of death," he said, in an apparent ad-lib, this spring in a speech at Tufts University. The pandemic, he told KFF Health News, helped "crystallize" his need to tackle misinformation. It was a "blatant case," in which multiple studies gave evidence about very effective therapeutics against COVID. "And a lot of people chose not to do it." There were "large-scale purveyors of misinformation," he said, poisoning the well.

Occasionally, though, Califf and the FDA have added to the cacophony of misinformation. And sometimes their misinformation is about misinformation.

Califf hasn't been able to consistently estimate misinformation's public health toll. Last June, he said it was the "leading cause of meaningful life-years lost." In the fall, he told a conference: "I've been going around saying that misinformation is the most common cause of death in the United States." He continued, "There is no way to prove that, but I do believe that it is."

At other times, as in April, he has called the problem the nation's "leading cause" of premature death. "I'll keep working on this to try and get it right," he said. Later, in May, he said, "Many Americans die or experience serious illness every year due to bad choices driven by false or misleading information."

Americans' health is indeed in dire straits. The Centers for Disease Control and Prevention noted the country's life expectancy has dropped two years in a row — it's at 76.1 years as of 2021 — a dismal capper to four decades of lagging gains. Countries such as Slovenia, Greece, and Costa Rica outrank the U.S. Their newborn citizens are expected to live more than 80 years, according to the Organization for Economic Co-operation and Development.

Several factors are at the root of those differences. But Americans' choices, often informed by bad or misleading data, political jeremiads, or profit-seeking advertising, are among the causes. For instance, one 2023 paper estimated that undervaccination against COVID — caused in part by misinformation — costs as much as $300 million per day, accounting for both the costs of health care and economic costs, like missed work.

Outside experts are sympathetic. Misinformation is a "huge problem for public health," said Joshua Sharfstein, a Johns Hopkins University public health professor and former FDA principal deputy commissioner. Having a strategy to combat it is crucial. But, he cautioned, "that's the easiest part of this."

The agency, which regulates products that consumers spend 20 cents of each dollar on per year, is putting more muscle behind the effort. It's begun mentioning the subject of misinformation in its procurement requests, like one discussing the need to monitor social media for misinformation related to cannabis.

The agency launched a "Rumor Control" page seeking to debunk persistent confusion. It also expects to get a report from the Reagan-Udall Foundation, a not-for-profit organization created by Congress to advise the FDA. Califf has said he thinks better regulation — and more authority for the agency — would help.

Califf has noted small victories. Ivermectin, once touted as a covid wonder drug, "eventually" became one such win. But, then again, its use is "not completely gone," he said. And, despite winning individual battles, his optimism is muted: "I'd say right now the trend in the war is in a negative direction."

Some of those battles have been quite small, even marginal.

And it's difficult to know what to take on or respond to, Califf said. "I think we're just in the early days of being able to do that," he told KFF Health News. "It's very hard to be scientific," he said.

Take the agency's experience last fall with "NyQuil chicken" — a purportedly viral cooking trend in which users roasted their birds in the over-the-counter cold medicine on social media platforms like TikTok.

Califf said his agency's "skeleton crew" — at least relative to Big Tech giants — had picked up on increasing chatter about the meme.

But independent analyses don't corroborate the claim. It seems much of the interest in it came only after the FDA called attention to it. The day before the agency's pronouncement, the TikTok app recorded only five searches on the topic, BuzzFeed News found in an analysis of TikTok data. That tally surged to 7,000 the week after the agency's declaration. Google Trends, which measures changes in the number of searches, shows a similar pattern: Interest peaked on the search engine in the week after the agency announcement.

Califf also claimed "injuries" occurred to participants "directly" due to the social media trend. Now, he said, "the number of injuries is down," though he couldn't say whether the agency's intervention was the cause.

Again, his assertions have fuzzy underpinnings. It's not clear what, if any, actual damage the NyQuil chicken fad caused. Poison control centers don't keep that data, said Maggie Maloney, a spokesperson for America's Poison Centers. And, after multiple requests, agency spokespeople declined to provide the FDA's data reflecting increased social media traffic or injuries stemming from the meme.

In countering misinformation, FDA also risks coming off as high-handed. In September 2021, the agency tweeted about purported myths and misinformation on mammograms. Among the myths? That they're painful. Instead, the agency explained that "everyone's pain threshold is different" and the breast cancer-screening procedure is more often described as "temporary discomfort."

Statements like these "erode trust," said Lisa Fitzpatrick, an infectious diseases physician and currently the CEO of Grapevine Health, a startup trying to improve health literacy in underserved communities. Fitzpatrick has previously served as an official with the District of Columbia's Medicaid program and with the CDC.

"Who are you to judge what's painful?" she asked, rhetorically. It's hard to brand subjective impressions as misinformation.

Califf acknowledged the point. Speaking to 340 million Americans is difficult. With mammograms, the average patient might not have a painful experience — but many might. "Getting across that kind of nuance and public communication, I think, is in its early phases."

Scrutiny over the agency's role regarding food and nutrition is also mounting. After independent journalist Helena Bottemiller Evich wrote an article criticizing the agency for relying on voluntary reporting standards for baby formula, Califf tweeted to correct a "bit of misinformation," saying the agency did not have such authority.

An agency communications specialist made a similar intervention with New York University professor Marion Nestle, referring to a "troubling pattern of articles with erroneous information that then get amplified." The agency was again seeking to rebut arguments that the agency had

erred in not seeking mandatory reporting.

“As I see it, the ‘troubling pattern’ here is FDA’s responses to advocates like me who want to support this agency’s role in making sure food companies in general — and infant formula companies in particular — do not produce unsafe food,” Nestle retorted. Notwithstanding the agency’s protests to Evich and Nestle, the agency had only recently asked for such authority.

Efforts to respond to or regulate misinformation are becoming a political problem.

In July, a federal judge issued a sweeping, yet temporary, injunction — at the instigation of Republican attorneys general, multiple right-wing political groups, and prominent anti-vaccine advocate Robert F. Kennedy Jr.’s Children’s Health Defense — barring federal health officials from contacting social media groups to correct information. A large section of the ruling detailed efforts by a CDC official to push back on suspected misinformation on social media networks.

An appeals court later issued its own temporary ruling — this time countering the original, sweeping order — nevertheless underscoring the extent of pushback on government pushback against misinformation. Califf has consistently played down the government’s ability to solve the problem. “One hundred percent of experts agree, government cannot solve this. We have too much distrust in fundamental institutions,” he said last June.

It’s a remarkable change from his previous tenure leading the agency during the Obama administration. “I would describe the Obama years as genteel, intellectual, and a lot of fun,” he has said. Now, however, Califf is bracing for more misinformation. “It’s just something that I think we have to come to grips with,” he told KFF Health News.

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