

The NIH ices a research project. Is it self-censorship?

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Many Americans don't understand a lot about their health. Whether due

to people believing conspiracy theories or simply walking out of their doctor's offices without a good idea of what was said, communicating what scientists know has been a long-standing challenge.

The problem has gotten particularly acute with a recent wave of misinformation. And when Francis Collins led the National Institutes of Health, the world's premier medical research agency, he thought he had a solution: to study health communications broadly. "We basically have seen the accurate medical information overtaken, all too often, by the inaccurate conspiracies and false information on social media. It's a whole other world out there," he said in 2021 as part of a farewell media tour.

"I do think we need to understand better how—in the current climate—people make decisions," he concluded.

But Collins' hopes appear dashed. In a sudden reversal, the NIH's acting director, Larry Tabak, has paused—some say killed—the planned initiative, Advancing Health Communication Science and Practice. Its advocates fear the agency has, for political reasons, censored itself—and the science that would've sprung out of this funding stream.

The agency has offered shifting and inconsistent explanations, sometimes outright contradicting itself in the space of days. Sources familiar with the project insist that whatever the agency's official story, it has acted unusually, contrary to its normal procedures in deciding what science to fund.

The officials, both in and outside of NIH, believe the agency is acting in response to political pressures over misinformation and is effectively censoring itself. Efforts to study or push back on inaccurate information have become contentious. The Republican-controlled House of Representatives repeatedly has plunged into the issue by investigating

social media firms and [government agencies](#) for their efforts to regulate online speech. They've even targeted academics who merely study information flows online. Meanwhile, in July, a [federal court](#) in Louisiana issued a decision on a long-simmering lawsuit brought by a group of Republican attorneys general and anti-vaccine groups to block [government officials](#) from communicating with [social media](#) companies, with certain exceptions for national security and criminal matters. That ruling has since been stayed.

Even though the NIH has had to navigate political rapids for decades, including enduring controversy over [stem cell research](#) and surveys on the sexual behavior of teens, this is a particularly fraught moment. "It is caught up in a larger debate about who gets to decide what is truthful information these days," said Alta Charo, a professor emerita of law and bioethics at the University of Wisconsin-Madison who has advised the NIH in the past.

For researchers interested in the topic, however, it's a major loss. The program was deemed potentially so important that it would be supported through the agency's Common Fund: a designation for high-priority programs that cut across normal institutional boundaries. In theory, it would study how health communication works, not merely at an individual doctor-to-patient level, but also how mass communication affects Americans' health. Researchers could examine how, for example, testimonials affect patients' use of vaccines or other therapies.

Serious money was on the table. The agency was prepared to spend more than \$150 million over five years on the endeavor.

For researchers, it's a necessary complement to the agency's pioneering work in basic research. The NIH has "done a remarkable job discovering the way cells communicate with each other," said Dean Schillinger, a researcher at the University of California-San Francisco. "When it

comes to how people communicate to each other—doctors to patients, or doctors with each other—the NIH has been missing in action." Now, he said, the tentative efforts to reverse that are met with a "chilling effect." (Schillinger co-authored an opinion piece in JAMA on these developments.)

After favorable reports from an agency's advisory body last fall, advocates were anticipating more encouraging developments. Indeed, the NIH's budget had touted the concept as recently as March. And participants expected the grant application process would begin toward the end of the year.

Instead, researchers have heard nothing through official channels. "Investigators have been asking, 'What's the plan?'" said Schillinger. Officially, "it's been the sound of silence, really."

That has been a puzzling anticlimax for a program that seemed to have all the momentum. "Given the urgency of misinformation, you would expect—within a year—a formal announcement," said Bruce Y. Lee, the executive director of the City University of New York's Center for Advanced Technology and Communication in Health.

Advocates and sources involved with the process had been pleased with its progress leading up to Tabak's sudden reversal. After Collins publicly floated the concept in late 2021, the agency took some public steps while defining the project, including holding a workshop in May 2022, keynoted by Collins.

Later that year, the project's leaders presented the concept to the agency's Council of Councils, a group of outside researchers who provide feedback on policy initiatives and projects. It got a warm reception.

Edith Mitchell, an oncologist at Thomas Jefferson University Hospital in Philadelphia, said the agency had a "major task, but one that is much needed, one that is innovative." The council gave the proposal a 19-1 seal of approval.

Researchers were happy. "As far as I was concerned, this program had been funded, accepted, and approved," Schillinger said. (The agency says that it is "not unusual" for programs not to move forward but that it does not track how frequently programs get affirmative votes from the council and later don't move forward.)

That smooth sailing continued into the new year. In March, the program was mentioned in the NIH budget as one of the agency's potential projects for the coming years. Then, say sources in NIH and elsewhere in government, came Tabak's sudden decision in April, which was not communicated to some researchers until June.

Early that month, Schillinger said, he received a call from an NIH official saying, "The program has been killed." Program officers were reaching out to academics who had made prior inquiries about the initiative and potential research efforts that could garner grants. Schillinger said researchers were told, "You're not getting an email" from the agency.

A former White House staffer and two current NIH officials—who were granted anonymity because they didn't have permission to speak on sensitive matters—said the decision, which came as researchers and agency officials were preparing to open grant applications in the last quarter of the year, was made by Tabak. KFF Health News asked Tabak for an interview but instead got an answer from agency spokespeople.

The agency disputes any final decision about this research funding that has been made. Spokesperson Amanda Fine told KFF Health News the

project was "still in concept phase" and is "being paused to consider its scope and aims."

But the agency lists the health communications proposal on the "former programs" part of its website, and sources inside and outside of government disagree with this company line. They point to political fears on NIH's part as driving the change, which reflects the growing political controversy over studying anything related to misinformation, even though the proposal was set up to examine health communications broadly, not solely misinformation.

A hint of this reasoning is contained in the rest of Fine's statement, which notes the "regulatory and legal landscape around communication platforms." When pressed, the agency later cited unnamed "lawsuits."

That's likely a reference to the Louisiana case, which was decided weeks after the agency decided to pause or kill the Common Fund initiative.

Fine later offered a new explanation: budgetary concerns. "We must also balance priorities in view of the current budgetary projections for fiscal years 2024 and 2025," she wrote.

That explanation wasn't part of a June 6 note on the program page, and one NIH official confirmed it wasn't part of previous discussions. When pressed further about the agency's budgetary position—which analysts with TD Cowen's Washington Research Group think will be flat—spokesperson Emily Ritter said, "The NIH does not have a budget projection."

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