Questions Surround “Paused” NIH Health Communication Research Program

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In a round of interviews before he stepped down as director of the US National Institutes of Health (NIH) in December 2021, Francis Collins, MD, PhD, frequently discussed the problem of misinformation, which, many argue, became more rampant during the COVID-19 pandemic, thanks in large part to social media.

Some have used the term “infodemic” to describe the glut of COVID-19 information—much of it false or misleading—on social media. During a disease outbreak, an infodemic “causes confusion and risk-taking behaviors that can harm health” and “leads to mistrust in health authorities and undermines the public health response,” according to the World Health Organization.

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When asked about the NIH’s role in pushing back against misinformation, Collins told Nature, “I wish we had more insights from behavioral social science research into how this has come to pass, and why it could have gotten so completely widespread.”

At the end of Collins’ tenure as NIH director, the agency planted the seed of a new program to support that very kind of research.

The NIH Common Fund would pay for the proposed program, entitled Advancing Health Communication Science and Practice. As its website notes, the Common Fund supports “high-risk, innovative endeavors with the potential for extraordinary impact” that are a high priority for the NIH as a whole.

The Common Fund convened a workshop in May 2022 to discuss “research opportunities and gaps for health and science communication.” Collins, at the time President Joe Biden’s acting science advisor, kicked off the workshop with a talk on federal priorities for health communication.

In September, the NIH Council of Councils approved the Advancing Health Communication Science and Practice program concept. A month later, the National Cancer Institute’s Behavioral Research Program enthusiastically tweeted about it, saying the program planned “to investigate and share new #community-engaged #equity-focused ways of #HealthCommunication and #SciComm.”

As stated by the Common Fund, the program’s objectives were to “investigate, develop, test, and disseminate new approaches for effective and equitable health communication,” an effort that would include addressing misinformation. The 5-year program would partner its research with technology and social media platforms, marketing experts, and health information communicators. The budget was set at $154.3 million, a tiny share of the NIH’s 2023 fiscal year budget of $47.5 billion but a windfall for health communications researchers.

Health communication has not traditionally been part of the NIH funding portfolio, psychologist Valerie Reyna, PhD, who spoke on a panel at the Common Fund workshop, pointed out in an interview with JAMA. Instead, the agency’s mindset has been “We developed the research. We find the medications. We find the cures,” said Reyna, codirector of Cornell University’s Center for Behavioral Economics and Decision Research and director of the university’s Human Neuroscience Institute. “And then they say, ‘Here are the cures. We’re done.’”

In reality, Reyna explained, “there’s far more to it than that. We realized that writ large during the COVID pandemic.”

Perplexing Pause

Eager to get to work on new projects to counter the infodemic, scientists in the field expected the new NIH health communication program to post a funding announcement last fall, but its website was never updated with that information.

This past spring, some researchers who’d expressed an interest in the program began receiving phone calls notifying them that the NIH had “paused” it. Others learned that the program had been halted when they checked its now archived web page, last reviewed June 6.

“I am disappointed,” epidemiologist Monica Ponder, PhD, an assistant professor of health communication and culture at Howard University, said in an interview. “It would have been a significant and validating milestone for our field.”

Ponder, who spent 14 years as a health communicator at the US Centers for Disease Control and Prevention (CDC) before leaving early in the COVID-19 pandemic, spoke on the Common Fund workshop panel with Reyna and had planned to apply for a grant. Ponder is the colead researcher on the Racial Ethnic Framing of Community-Informed and Unifying Surveillance (REFOCUS) project. Funded by the CDC Foundation, the project examines racism in COVID-19 crisis communication.

The NIH’s explanation for why it halted the health communication program seems to raise more questions than it answers: “NIH has decided to pause moving forward with the development of the program to reconsider its scope and aims in the context of the current regulatory and legal landscape.
around communication platforms, its web page states.

“It’s not a very transparent statement,” Richard Baron, MD, president and chief executive officer of the American Board of Internal Medicine, noted in an interview. He coauthored a JAMA Viewpoint about the halting of the program.

Collins, who is continuing to conduct research at the NIH, did not respond to JAMA’s interview request for this story but instead forwarded the email to the agency’s media relations staff. They responded with a statement that echoed the explanation on the program’s web page and added, “We must also balance priorities in view of the current budgetary projections for fiscal years 2024 and 2025.”

The projected annual cost of the 5-year program, approximately $31 million, represents about 0.06% of the NIH’s 2023 fiscal year budget.

“I was looking forward to this funding mechanism,” clinical psychologist Sherry Pagoto, PhD, director of the UConn Center for mHealth & Social Media, said in an interview. “My program of research is shaped very much by what ends up getting funded.”

Pagoto and other researchers who’ve studied or written about the spread of misinformation suspect a more sinister reason behind the decision to halt the Advancing Health Communication Science and Practice program than what the NIH has provided: political pressure.

“Even though it may not be a ton of money, if it’s a sign they’re moving away from this topic because they’re getting a lot of intimidation, that would be a concern,” Pagoto said.

General internist Dean Schillinger, MD, director of the University of California, San Francisco, Health Communications Research Program, was also planning to apply for a grant from the program.

“There is something going on here that has forced the NIH’s hand,” Schillinger, who coauthored the JAMA Viewpoint with Baron, said in an interview. “I truly honor and respect the leadership of the NIH, and I can only imagine this has been a very difficult decision made over someone’s dead body, and it’s a crying shame.”

Free Speech or Propaganda?

Baron can’t help but think of the Dickey Amendment when musing about why the NIH halted a program that would have funded health communication research.

The late US Rep Jay Dickey, an Arkansas Republican, introduced the amendment, part of the Omnibus Consolidation Appropriations Act of 1997, after heavy lobbying by the National Rifle Association. “[N]one of the funds made available for injury prevention and control at the Centers for Disease Control and Prevention may be used to advocate or promote gun control,” it read.

The amendment—a response to a CDC-funded study that concluded having a gun in the home was associated with a higher risk of homicide by a family member or intimate acquaintance—had a chilling effect on research related to gun violence for 2 decades. Not until 2018 did Congress clarify that the CDC could conduct gun violence research.

“This to me has that odor to it,” Baron said of the NIH’s decision to pause the health communication program. “They’re backing away from research that could save lives because there’s some political agenda they’re afraid they’re going to run afoul of.”

In this case, Baron said, the political agenda appears to center on the debate over whether people who make claims on social media that go against public health recommendations are simply exercising their First Amendment right to free speech.

Is it free speech to blog that COVID-19 vaccines have killed more children than the disease itself, manipulating data to prove one’s point? Is it free speech to tout the antiparasitic drug ivermectin as an effective COVID-19 treatment despite clinical trial data to the contrary?

Although some would answer, “Yes,” the First Amendment doesn’t protect all speech, Baron noted. “Freedom of speech is not absolute,” he pointed out. “Fraudulent speech is illegal.” For example, he said, when physicians are slapped with malpractice suits for giving bad advice, “they don’t get to say, ‘I have the free speech right to say this.’ They don’t.”

Ponder described “messages that distract or demotivate people from pursuing a healthy life” as propaganda, not free speech.

“Our intent as scientists was not to take down those who are conveying this information,” Schillinger explained. “That’s the responsibility of social media platforms should they choose to do that.” Instead, he said, he and other researchers hoped to use the NIH grant money to create “compelling, actionable information” to serve as a counterweight.

“We have to stand up and say expertise matters,” Reyna said. “That doesn’t mean people can’t offer opinions. They have to say: ‘This is my opinion,’ as opposed to [this is] what the science says.”

The Legal Landscape

The NIH’s explanation for why it paused the health communication program cited “the legal landscape around communication platforms,” apparently referring to a lawsuit, Missouri v Biden, filed in early May 2022—just days before the NIH Common Fund workshop.

Plaintiffs include Missouri’s Republican former attorney general, now a US senator; Louisiana’s Republican attorney general; and Stanford University health care economist Jayanta Bhattacharya, MD, and Harvard University biostatistician Martin Kulldorff, PhD. Bhattacharya and Kulldorff were 2 of the 3 authors of the October 2020 Great Barrington Declaration, which condemned the COVID-19 lockdowns recommended by public health officials. It urged reopening schools because “for children, COVID-19 is less dangerous than many other harms, including influenza”—an assertion that has been challenged by subsequent studies, including one published this past January in JAMA Network Open that found COVID-19 was the deadliest of all infectious and respiratory diseases among US children and adolescents.

Defendants in the lawsuit include President Biden; Surgeon General Vivek Murthy, MD, MBA; US Health and Human Services (HHS) Secretary Xavier Becerra; the US Food and Drug Administration; the US Election Assistance Commission—the suit conflates claims about the 2020 presidential election with those about COVID-19—and numerous other federal agencies and officials.

The suit accuses the Biden administration of “open collusion with social-media companies to suppress disfavored speakers, viewpoints, and content on social-media platforms under the Orwellian guise of halting so-called ‘disinformation,’ ‘misinformation,’ and ‘malinformation.’” In particular, it claims that the defendants suppressed conservative-leaning free
speech about such topics as the efficiency of face masks, lockdowns, and vaccines in preventing the spread of COVID-19. It also claims that the Biden administration suppressed speech about the integrity of the 2020 presidential election and the security of voting by mail.

On the Fourth of July, federal Judge Terry Doughty in Louisiana granted a preliminary injunction saying that parts of the government, including HHS and the Federal Bureau of Investigation, couldn’t talk to social media companies for “the purpose of urging, encouraging, pressuring, or inducing in any manner the removal, deletion, suppression, or reduction of content containing protected free speech.” However, the Biden administration on July 10 filed an emergency motion seeking a stay of the preliminary injunction, a request that the US Court of Appeals of the Fifth Circuit granted on July 14.

Meanwhile, on July 20, weeks after the NIH halted the health communication program, Jim Jordan, an Ohio Republican who chairs the House Judiciary Committee, and Rand Paul, MD, a Kentucky Republican who serves as the ranking minority member of the Senate Homeland Security and Governmental Affairs Committee, introduced the Free Speech Protection Act.

Echoing claims made in Missouri v Biden, the bill says that officials at the White House and executive agencies “sought to silence narratives on social media platforms on issues relating to the COVID-19 pandemic.” The bill goes on to say that the CDC asked Facebook and Twitter officials to flag certain posts as disinformation and regularly met with the companies about “what government officials determined to be ‘misinformation’ about the COVID-19 pandemic spread on the platforms.”

If passed into law, the act would prohibit federal grants “relating to programming on misinformation or disinformation.” Republican members of Congress have sent letters to at least 3 universities—Stanford University, the University of Washington, and Clemson University—and the German Marshall Fund of the United States requesting documents and information related to the moderation of social media content, ProPublica reported in March. A letter signed by Jordan that was obtained by ProPublica said the request was part of an investigation into how “certain third parties...may have played a role in this censorship regime by advising on so-called ‘misinformation.’”

Also in March, a group called “Protect the Public’s Trust” sent 3 Freedom of Information Act (FOIA) requests to the University of Connecticut asking for records of all communication since June 1, 2020, between employees working on a National Science Foundation (NSF)-funded study and several federal agencies, individual current and former federal employees and other individuals, and the social media platforms Twitter and Facebook. Pagoto is one of the study’s 3 principal investigators, all at UConn.

The “Bias Reduction in Medical Information” study, for which UConn received a $393,000 NSF grant in fiscal year 2022, is focusing on using artificial intelligence “to detect and mitigate biased, harmful, and/or false health information that disproportionately hurts minority groups in society,” according to the NSF, an independent federal agency that supports science and engineering. The NSF was contacted by JAMA for this story but did not provide a comment by deadline.

Anthony Fauci, MD, former head of the National Institute of Allergy and Infectious Diseases, and Murthy, the US Surgeon General, are the best-known of the individuals named in the FOIA requests, which Pagoto shared with JAMA. Perhaps the most unlikely organization on the list, considering that Pagoto and her colleagues are health communications researchers, is the Election Integrity Partnership, another example of the conflation of the 2020 presidential election and the COVID-19 pandemic.

“When I got the FOIA requests, I was very scared,” Pagoto said. “Who are these people?”

The FOIA requests were signed by Morgan Yardis, identified as a Research and Publication Associate at Protect the Public’s Trust. Between May 2021 and late July 2023, Yardis filed dozens of FOIA requests to federal agencies, mainly the Environmental Protection Agency and the National Labor Relations Board, on behalf of Protect the Public’s Trust, a search on FOIAonline.gov found.

The FOIA requests to UConn say “reports have revealed” that the NSF spent nearly $39 million on government grants and contracts, including to 42 colleges and universities, “to combat the spread of misinformation.”

“Many Americans are concerned that such efforts have infringed, and will infringe, upon the First Amendment rights of American citizens,” the FOIA requests say, adding that the “federal government’s disturbing commitment to spending taxpayer dollars to fund research on how best to censor speech is undoubtedly alarming.”

Pagoto noted, “In my entire career, I’ve never been told I’m a threat to democracy.”
Protect the Public’s Trust has sued at least one institution for taking too long to respond to a FOIA request. Last December, the group filed a complaint in King County Superior Court against the University of Washington for not supplying records of communications between faculty member Kate Starbird, PhD, and employees within a variety of organizations, including the NAACP and the Defending Digital Democracy Project at Harvard. Starbird is an associate professor of human design and engineering at the university and cofounder of its Center for an Informed Public, which has a stated mission “to resist strategic misinformation, promote an informed society, and strengthen democratic discourse.”

The FOIA requests to UConn describe Protect the Public’s Trust as “a nonpartisan organization dedicated to promoting ethics in government and restoring the public’s trust in government officials.” The group’s website lists no information about its funders or the names of any staff other than its director, Michael Chamberlain. According to what appeared to be his LinkedIn profile, Chamberlain led Nevada communications for Trump’s 2016 presidential campaign and worked for the US Department of Education under Betsy DeVos, Trump’s education secretary.

No matter what such groups as Protect the Public’s Trust and the Jordan-chaired subcommittee do with the information they obtain, their numerous FOIA requests seem to be accomplishing one goal: the chilling of discourse around misinformation research.

FOIA requests “have been weaponized by people who recognize how time-consuming they are,” Claire Wardle, PhD, cofounder and codirector of Brown University’s Information Futures Lab, told JAMA in an interview. “Many other people and I do a lot less posting on social media. We do a lot fewer conference appearances,” she said. “That’s what makes it so sad.”

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Conflict of Interest Disclosures: Dr Reyna reported receiving research grants from federal research agencies on topics including medical decision-making and public health; presenting research talks at universities and research conferences; having served as an expert advisor and in leadership roles for many academic and scholarly organizations, including the NIH and the NSF; and advising the World Health Organization on a project with Meta on public health messaging. Dr Pagoto reported receiving funding from Meta to create educational content, Weight Watchers International, the NIH, and the NSF and serving as a paid advisory board member for Weight Watchers International and Astellas Pharmaceuticals. Dr Wardle reported having consulted for the Office of the Surgeon General and the CDC. Dr Baron reported serving as CEO of the American Board of Internal Medicine and the ABIM Foundation. No other disclosures were reported.

Note: Source references are available through embedded hyperlinks in the article text online.