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Anger, despair, and defiance from a voice within the US federal research system

People around the world are watching with disbelief as the new US government closes down its aid programme, withdraws from the World Health Organization (WHO) and the Paris agreement on climate change, deletes datasets that do not fit with its ideology, refuses to pay adequate overhead to universities—so halting research and bankrupting many, and insists that certain words are not used in federal documents, including federally funded research. The words that must not be used include bias, biased, women or female, and it's impossible to see how scientifically valid research can be conducted without these words: we won't, for example, be able to write about risk of bias in a sample of women, who make up half the population.

The speed with which this has been done has created the intended shock and awe among the opposition, which has been slow to respond. What is happening upends everything we have been taught about the checks and balances of our nation. We begin now to see opposition, not least from journals and lobbying groups. But one group you may not hear from are those inside the federal system. You have not heard from us because we are terrified of the response—not just having our research cancelled and being summarily dismissed, but also set upon by the 250 million followers of Elon Musk on X. Our homes, salaries, families, and even our lives are at risk.

I am a researcher within the federal system, and I hope that you will forgive me and understand why I am publishing this piece anonymously. The very fact that I am having to publish this anonymously in a country that has the right to free speech written into our Constitution is an indictment of what is happening. Like all federal employees in the US, I took an oath to the Constitution, not to a president or political party. I should be able to speak out without fear, but the judicial system is slow to react, appears overwhelmed with more important complaints than from one scientist, and perhaps has been compromised.

I never thought that in the US we would come to fear the knock on the door as so many have feared in unfree countries. The fear of speaking about this to friends and close colleagues because we do not know who believes what. Free speech and the rule of law have been central to what the US stands for and what it has achieved, but both now are being eroded.

We have been handed a huge list of words that may lead to a grant being pulled, including advocacy, biased, gender, LGBT (lesbian, gay, bisexual, transgender), diversity, inclusion, marginalised, and underserved.

We have been told to remove references to vulnerable groups and retract or pause the publication of any research manuscript being considered by any medical or scientific journal which uses these words.

The Center for Disease Control (CDC) and other federal organisations with health datasets have been told to remove data that relates to "gender ideology" even if it is not the same as the Diversity, Equity, and Inclusion (DEI) that is now considered so damaging. Removing these demographic data that track populations at risk will mean that community leaders and programme managers will no longer have evidence for decision making or resource allocation for those who need healthcare the most. This is digital genocide: populations of vulnerable people are being deleted. Data on transgender men and women are being deleted. We are also losing data on maternal mortality. These populations will suffer now and for decades to come. The US will be unable to understand mortality and morbidity rates to tackle health inequalities because the data are forbidden. How can our leaders see this as a win when our neighbours and families will die?

Do our leaders understand how by withdrawing from WHO, censoring the Morbidity and Mortality Weekly Report, and turning our backs on global health we make ourselves more vulnerable to the pandemics that will inevitably come again? Not only the US but the whole world will be at greater risk. Data on epidemic or pandemic emerging infectious diseases will be unavailable as will early warnings and information on preparedness for preventable mortality and morbidity. The US performed poorly in the covid-19 pandemic with more than a million deaths and is setting itself up to perform even more poorly in the next—even this year's flu season is dangerously under reported. As always, it will be the most vulnerable who will die, this time unrecorded. There is a measles outbreak in Texas, the heart of the anti-vax movement. The data are slow to emerge and coming only from the state level. A tuberculosis outbreak is spreading in the middle part of the country. These are trying times.

Health websites across the US government have gone dark. Resources on contraception, HIV, sexually transmitted infections, and avian influenza have disappeared. A portal on maternal morbidity and mortality is unavailable. The National Institutes of Health office of women's health's information on "supporting women in biomedical careers" and "women's health funding opportunities" has gone. Efforts to bring women into science and medicine that have been decades in the making are undone.

Inside the US federal scientific community, we are not hopeful. As members of the science, medical, and public health community, we worry about our global community as we see preventable deaths stacking up abroad and across the US—especially among the most vulnerable. Digital genocide will undo decades of progress towards informed and appropriate care and those who are female, non-white, poor, and living in Republican states will suffer disproportionately. As researchers we have spoken for the voiceless, and now we are gagged. Our friends and colleagues have been put on administrative leave and are unable to participate in life saving work. How can leaders make evidence informed decisions if there is no evidence?

What we have experienced in the past few weeks is like a death in the family. We are angry, shocked, and saddened, but we must not despair: we must hold the line. How can we work within this greatly changed system to keep America healthy? How can we care for all Americans in the face of digital genocide? We must honour our oath to the Constitution and to the great experiment that is America.

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