

# A refusal to abandon HIV science

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Recent, ideology-driven attacks on public health from the new US administration have potential to eviscerate lifesaving gains of HIV science and clinical practice. The US Agency for International Development has been physically dismantled, with an estimated 151 946 jobs lost globally to date [1]. The HIV Modelling Consortium estimates that there will be an additional 159 000 adult deaths, 4230 infant deaths, and 90 000 additional infant HIV infections this year [2]. Modeling in South Africa and across African settings suggest that this year will see 109 552 excess deaths attributable to HIV/AIDS [3,4].

None of these estimates begin to account for the suffering that will accompany erasure of food security, decimation of scientific expertise, and eroded health systems [5,6]. Clinics across the globe have shuttered, leaving providers suddenly unemployed and patients with no source of care [7]. Websites with vital information are purged, and global partners forced to pull health education resources [8]. So far, the US National Institutes of Health has stripped 76 funding calls and frozen research that includes diversity or gender [9].

The purpose of these antiscience actions is to induce a culture of fear. Names of scientists doing cutting-edge research are being listed in what can only be referred to as hit lists. Federal employees are encouraged to report on peers who might still be working according to their mandate as civil servants. Universities and research organizations are doing little to protect HIV researchers or students, and are actively encouraging self-censorship or silencing to navigate the current political reality.

As an HIV field, we can and must do better. As citizens, we can choose to use our rights to look reality clearly in the face instead of fleeing from it. As scientists, we can use our prestige and training to push back with focus and intent. We propose several principles that can guide HIV efforts in light of the US-led censorship, funding freezes, and attacks on the scientific enterprise.

## Principle 1. Remember that social movements drove our field

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HIV science was built on the shoulders of fierce activists all over the world, and has enjoyed exceptional financial investment because of those who protested, fought, and suffered to make it so. For example, lifesaving medication is available globally because activists in South Africa, Brazil, and India organized and fought to bring down prices through domestic manufacture and patent protections [10]. Patent pools lead not only to longer lives and HIV-free infant survival, but to economic growth; for every \$1 invested in patent pools, we save \$43 in patient costs [11].

Many of the visionaries of the HIV field were and continue to be queer, transgender, decolonial, Black, brown, and indigenous activists [12–15] who themselves draw on LGBTQ activism in Compton and Stonewall in the 1960s [16]. This history of HIV science makes it an affront to our field that the US National Park Service has

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erased transgender people from the Stonewall national monument.

HIV researchers have, in our best moments, worked in solidarity with and followed the leadership of patient-activists driving these movements. Our careers rest on the building blocks that these courageous leaders laid down for us. At this pivotal moment in world history, we have a unique obligation to reciprocate these efforts by standing firmly with the communities to whom we have dedicated our careers. Rather than focus on academic and professional self-preservation, we must again listen closely to communities of activists and frontline practitioners, follow their lead, and offer our service.

## **Principle 2. Do not comply in advance**

Many institutions are rushing to comply and over-comply with the administration's executive orders to a shocking degree. Institutions have scrubbed mention of essential topics from social media feeds. Professional societies have dropped their equity efforts from websites. Universities and federal agencies are pulling manuscripts or disallowing their publication with certain words.

We mourn with colleagues across the globe who have received stop work orders from US institutions requiring that they halt specific programming. At the same time, it is unconscionable to rush toward over-compliance in anticipation of favors or retribution. When we are asked to comply with the abhorrent, noncompliance becomes a virtue. The next phase will require action only when unambiguously legally required or if you are rescinding your scientific integrity to political attempts to rewrite reality.

## **Principle 3. Retain precise language**

It is obvious that lists of words that “do not align with administration priorities” amount to scientific censorship [17]. Some propose we can avoid the censor's pen through the use of alternative language.

We posit that those of us who generate knowledge—through papers, policies, and other public scholarship—have a responsibility to continue using accurate words and concepts in our HIV science. Ceding language now will undo decades of progress toward destigmatizing and illuminating the contributions of marginalized communities disproportionately affected by HIV. Erasing these communities behind the guise of “hidden” populations is an affront to the visibility for which they have fought so hard.

We owe it to our field and the scientific profession to employ words accurately to name the world around us. Language has meaning and we must not cede it before the law requires us to. Transgender youth are a community deserving of healthcare that meets their needs. Racism is real and profoundly shapes the world we live in. People with disabilities have a right to be seen, named, and included. If we stop using intentional, accurate language we capitulate to a world in which vulnerable populations are simply written out of existence.

## **Principle 4. Harness collective power in explicit and subtle ways**

As scientists, clinicians, and people with lived experience, we must band together. We can refuse to abandon anyone, and to use whatever social power we possess with care and attention on behalf of others. Academic power in the moment takes the form of relative safety from retaliation, which may occur in many ways: legally-recognized residency status; tenured academic appointments; alternate sources of income; ability to leverage or pivot to a line of research that is relatively well tolerated from current censorship and funding cuts; or simply presenting as white, cisgender, heterosexual, able-bodied or other traits that are not currently in the cross-hairs. We must leverage our influence, relative safety, and scientific expertise to influence deans, presidents, and boards of our institutions. We can organize vigils that honor the lives already lost due to the antiscience agenda and join in public, peaceful protest.

A new vision for HIV science demands support from private foundations, wealthy individuals, and pharmaceutical companies. These groups whose generational wealth and revenue streams were built, in part, thanks to HIV science and the extraordinary communities who take part in treatment, prevention, and care discoveries. Philanthropies will need to commit to promising programs *and* to the evidence base that is needed to support HIV work. This will mean spending more on research funding than during “business as usual” phases of work. It will also mean compelling our institutions to redirect donor investment and university endowments *towards* scientific fields that are being censored.

It is important to note that HIV collective activism often takes place in quieter, less public ways [18,19]. These “ethics of care” or “mutual aid” can guide our actions in the coming phase, and will add to our own ability to weather this assault on science. We can meet one-on-one with students and junior colleagues and ask what their priorities are, and speak up at faculty meetings to table these points. We can text students to say we are committed to their growth, and follow through with

an opportunity to co-write an op-ed or statement of solidarity. When we converse with colleagues, we can declare our accurate concerns, rather than offering empty promises of a future we can no longer bank on.

## Principle 5. Acknowledge that each affront to HIV science is connected

It can be tempting in this fast-moving and uncertain time to retreat. We may focus our attention on narrow actions that place our own research or practice at acute risk, rather than staying connected to and in solidarity with our colleagues and communities. For example, many institutions were silent when care for young transgender patients was banned, but spoke out when indirect funding cuts were tabled.

A siloed approach is untenable. Indirect attacks on science funding and direct attacks on some human bodies have the same goal: to make us quiet and fear fighting back together. Too many loved ones, students, colleagues, and patients know in their bones how targeted hatred is deeply connected to the defunding of science: peer counsellors in PEPFAR-funded programs are suddenly unemployed and begging for food; imprisoned transgender women are forced into extreme risk of violence in men's facilities; patients are in need of clinical care but are afraid to visit a health center due to looming immigration raids.

Those of us still living in relative stability may feel commiserate camaraderie, albeit less existential or oppressive, when our project focused on improving health is cancelled without ceremony. Perhaps we notice the fear that grips us when our grant is listed on a right-wing list of topics that are suddenly censored. We must use these glimmers of humanity to our advantage, they point to how our livelihood and sense of safety is directly tied to the wellbeing and work of the communities we serve.

As an HIV field, we must mobilize around a research agenda that bolsters HIV research in spite of political censorship by the US executive branch. We must recognize HIV science and human flourishing as interconnected, and find ways to resist together, lest we fall separately, one by one.

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## Conflicts of interest

There are no conflicts of interest.

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