



Independent observer
of the Global Fund

THE UNCOUNTED: POLITICS OF DATA IN GLOBAL HEALTH

Meg Davis currently works at the [Graduate Institute for International and Development Studies](#) and teaches at the Geneva Centre for Humanitarian Studies in Geneva. This interview is excerpted from the [Hong Kong Journal of Law and Public Affairs \(HKJLPA\)](#). Her book, *The Uncounted: Politics of Data*, [comes out in paperback](#) tomorrow, October 1.

Q: Could you tell us more about your book, *The Uncounted: Politics of Data in Global Health*? What are its main arguments?

Meg Davis [MD]: The world is currently off track in the race to “end AIDS by 2030,” a goal set by UN member states in 2016. My book explains why: one reason we are off track is that the targets UN agencies set have focused global efforts on rapidly scaling up treatment programs. However, these are based on overly optimistic mathematical models which failed to take account of on-the-ground realities. You can fund the most wonderful HIV clinic in the world, but if the people who work there discriminate against those who are most vulnerable, your money is wasted. Data is used to make life-or-death decisions, but those most vulnerable to HIV are the “key populations”—sex workers, men who have sex with men, transgender people, people who use drugs—who are everywhere subject to discrimination, stigmatization and violence that drive them underground and leave them invisible, uncounted and unserved. HIV rates will continue to rise as long as they are left behind.

We’re all victims of a data paradox in which absence of evidence becomes evidence of absence: many governments deny the existence of key populations. States either fail to gather data on these populations, or because these populations are very sensibly hiding from the risk of arrest and public stigma, official data underestimates the actual size of the groups. The lack of data results in a lack of resources to fund HIV programs for these communities, which reinforces the lack of data, and in turn reinforces the official

denialism. Thus, overreliance on poor quality data to make decisions in public health can actually reinforce existing social and health sector discrimination. Worse, it can even lead health officials to mistakenly believe they are reaching key populations, when in fact most are not being reached.

The same problem applies to other taboo topics that affect health, such as sexual violence and intimate partner violence: absence of evidence is used as evidence of absence, and we fail to reach those who most need services. We are now seeing this problem with COVID-19 as well, with the failure to accurately measure the impact of the pandemic on marginalized groups, such as migrants in Singapore, or African American and Native American communities in the US. Additionally, everywhere persons with disabilities are perhaps the most invisible and underserved of all.

Q: How did you come about conceptualizing this book project?

[MD]: I worked for several years as the first senior advisor on human rights at the Global Fund to Fight AIDS, Tuberculosis (TB) and Malaria, then later as an advisor to civil society delegations on the Board of the Global Fund, including legendary Hong Kong AIDS activist, Loretta Wong. In that role, I often had to defend, or help others defend, the importance of funding work that addresses HIV- and TB-related criminalization and discrimination. For instance, legal aid services for HIV peer outreach workers who were working with sex workers and at risk of arrest. In these discussions, I had to constantly contend with the lack of quantitative data demonstrating that funding human rights programs had an impact on health outcomes.

These debates really forced me to confront the epistemological divide between health people, who favor quantitative evidence, and human rights activists and lawyers, who favor verbal evidence such as laws and testimony. Often I noticed that those groups have trouble hearing one another, even when they are in the same meetings. For instance, the International AIDS Conference is a huge biannual meeting and it's always the same: the public health people are in the big halls speaking to other quantitative health people with slides showing charts and numbers, while the human rights activists (myself included) are off in the smaller rooms preaching to the converted about their latest narrative report. Why?

Ultimately, I began to see that both groups are in a way, doing the same thing: both are creating signs or abstractions of complex realities, and using these signs to negotiate power and resources. Both words and numbers are powerful distillations of more complex realities. As an anthropologist, I began to see indicators and mathematical models in global health as sites of contest over power, and that is what I aimed to explore with the book.

Q: For readers who are not health professionals, what are your key messages to them?

[MD]: We are in a world in which our most intimate data is increasingly used to speak for us, to make life-or-death decisions, and it is important that we all insist on transparency and accountability for what data is used, who has it, who uses it, and what decisions are being made. It's especially important for us all to engage in the current global debate over digital surveillance and its limits.

Q: Overall, do you think increasing pressure from donors for higher data precision is a positive driving force in the global campaign to end AIDS?

[MD]: I think it's very hard to understand the complexity of that question without thinking about the history of colonialism. One figure who really summed up the complex challenges of this for me, and whom I had the privilege to interview for the book, was U.S. Ambassador Deborah Birx. Birx is one of the rare senior women in global health. As head of the largest bilateral funder for health, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), she has been a courageous champion of key populations and of young women at risk of sexual violence. She is renowned for demanding very granular data from governments

that would prefer to ignore those groups, and for using data to demand faster progress. So here the U.S. has played an important role in promoting the right to health.

But at the same time, this approach has very real downsides. Sometimes the data is gathered in ways that are intrusive, violate privacy and informed consent, and can increase risk of exposing those groups to violence or discrimination.

And the risk is not only to individuals, but to whole countries. In the book, I also show how the data-driven decision during Birx's tenure to abruptly pull funding from middle-income countries in the Caribbean (where there were smaller numbers of people living with HIV) in order to invest in African countries (where the numbers were larger and PEPFAR could get higher impact for its investment) was well-intentioned from the perspective of Africans, but also caused real harm to communities and governments in the Caribbean. Groups and governments in the Caribbean had no say in this life-or-death decision by the US, which was very reminiscent of abuses of power under colonialism.

I believe the PEPFAR case exemplifies both the real good and the real harm that global health donors can do with aid. It also highlights the much bigger problems, which PEPFAR and other health donors are wrestling with, of global rationing caused by a lack of resources for health. Today, of course, Birx and many others are dealing with similar challenges in the COVID-19 response: we are seeing the impact of a lack of health funding on a global scale.

Q: In your book, you have illustrated the paradox of global health data in the context of HIV. Regarding the problem of not gathering data about the more vulnerable population, you have suggested community empowerment, advocacy by local groups, etc. as keys to ending this paradox. How can that be done?

[MD]: I was privileged in the course of writing this book to be able to follow and observe a project led by Caribbean Vulnerable Communities Coalition, a regional human rights group, and researchers from the University of Alabama at Birmingham. Together they led a participatory action research project across six countries to gather data on key populations with the active involvement of those communities, as well as government officials, medical doctors, and civil society groups. They did an impressive job of positioning community groups in the center of the research, making them experts in their own data, giving them ownership and control, and thus positioning them to be ready to help lead the response once the study was done. The research was recognized with the Robert Carr Research Award recently.

I am now using the same approach to lead a new consortium of civil society groups and researchers, the Digital Health Rights Advisory Group (DRAG) which plans to spend two years working with community-based organizations to understand the human rights risks linked to digital technologies and artificial intelligence in health. Our plan is to utilize the research results in policy advocacy, at both country level and in global health agencies, in parallel with the research.

Q: What is, if any, the role of transnational organizations, like the World Health Organization (WHO), in demolishing the invisibility of these vulnerable populations in health data collection? Have they been successful in doing it?

[MD]: The challenge that UN agencies face in health data collection, and that the WHO is really contending with right now, is that they are essentially membership organizations, and the members are states. It can be quite difficult for UN officials to refuse to accept data presented to them by governments. This is where the roles of civil society groups, investigative journalists and independent academic researchers are so critical. We can address the 'elephant in the room', the taboo issue that no one wants to speak about, and share alternative evidence and insights from lived experiences. We can also blow the whistle on corruption and abuse. As the space for civil society organizations, scholars and media is decreasing in many countries, this is increasingly difficult work. Unless we ensure that the space remains

open, our global health data will be unreliable and subject to manipulation for political and financial interests; and we definitely won't end AIDS, or COVID-19 for that matter, without transparency and accountability.

Q: What were the challenges that you faced while writing the book?

[MD]: The main challenge I faced was that the research and writing were self-funded. As a mid-career independent researcher, there was no grant funding for someone like me, so I paid for almost all my travel and my time out of my own savings as a teacher and consultant. I was lucky to have wonderful employers who understood what I was trying to do and were supportive.

Q: A lot of the data and information in your book comes from the field. How did you ensure the accuracy and reliability of the data?

[MD]: I am obsessive about fact-checking. That does not mean there are no errors, but I certainly gave accuracy my very best effort.

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