We Are People

In an opinion piece titled "We Are People, Not Clusters!" Edwin Bernard, executive director of the HIV Justice Network, argues that molecular HIV surveillance risks doing more harm than good. Here is an edited excerpt.

January 4, 2021 By Edwin Bernard

Articles and editorials in the October 2020 issue of the American Journal of Bioethics examine the use of blood taken from people living with HIV during routine testing before they started or changed antiretroviral therapy. These samples were put in surveillance databases without our permission and used for public health purposes.

This is already taking place across the United States and in some Canadian provinces and is currently being considered elsewhere in the world.

The rollout of so-called molecular HIV surveillance to identify "clusters" of transmissions to attempt to further improve public health responses to HIV is a growing source of anxiety and concern for people living with HIV, especially for people who are already marginalized and criminalized in other ways, because they can't be certain that this data won't be shared with law enforcement or immigration authorities.

In our lead guest editorial, titled "We Are People, Not Clusters!"—which I coauthored with Alexander McClelland, Barb Cardell, Cecilia Chung, Marco Castro-Bojorquez, Martin French, Devin Hursey, Naina Khanna, Brian Minalga, Andrew Spieldenner and Sean Strub—we support the concept of "HIV data justice" put forth in the lead article, "Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice," by Stephen Molldrem and Anthony Smith.

From the Molldrem and Smith article: "HIV data justice draws on the collective resources of the HIV/AIDS movement to build new alliances [to provide] affected individuals and communities with greater control over how their data are utilized in the health care system, with the paired aim of providing them with greater access to better services on terms of their own choosing."

In the editorial, we welcome Molldrem and Smith's critique of the controversial rollout of molecular HIV surveillance (MHS) in the United States, which explores three intersecting concerns:

(1) the nonconsensual repurposing of personal health information and biomaterial for public health surveillance;

(2) the use of molecular HIV surveillance data in larger databases to find “clusters” of infections and to make determinations about transmission directionality and the criminalizing implications that follow such determinations; and

(3) the way MHS amplifies the targeting and stigmatization of already oppressed and marginalized communities.

The editorial questions the rationale behind the use of MHS as one of four pillars of the U.S. Centers for Disease Control and Prevention’s (CDC) End the Epidemic Plan and calls for the abolition of molecular HIV surveillance in the United States as it is being rolled out by the CDC. It blurs the boundaries between consent and criminalization.

Instead, we envision a future of new participatory and intersectional racial and viral justice possibilities, one that ensures the lives, self-determination, voices and autonomy of people living with HIV are central to HIV research and public health practice.

From our guest editorial: “This editorial is an act of refusal...to allow our bodies to be treated as troves of data, and as risks to be calculated. We are people to be consulted, to be heard, and to be engaged with, on all aspects of our lives. As such, this editorial is also a rejection of MHS and the public health practices of objectification.... Instead, we call for participatory and community-located, intersectional, racial and viral justice approaches to respond to HIV.

“In 1983, people living with HIV stood in front of medical professionals in Denver and stated: We condemn attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS.’

“Today, we add to this statement: We are people, not clusters!”

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http://beta.docker.poz.com/article/molecular-hiv-surveillance-edwin-bernard