We Are People, Not Clusters!

Advocates say public health surveillance using blood taken for HIV resistance testing risks doing more harm than good.

September 24, 2020 By Edwin Bernard

A series of articles and editorials in the October 2020 issue of the American Journal of Bioethics examine a growing concern amongst community leaders of people living with HIV and our scholarly allies: the use of blood taken from people living with HIV during routine testing prior to starting or changing antiretroviral therapy in surveillance databases, without our permisssion, 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 in the United States and Canada, 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, which can lead to prosecution and/or deportation.

In our lead guest editorial, entitled "We Are People, Not Clusters!" — which I co-authored 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 target article, by Stephen Molldrem and Anthony Smith, "Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice."

From the Molldrem and Smith article:

> HIV data justice draws on the collective resources of the HIV/AIDS movement to build new alliances aimed at providing affected individuals and communities with greater control over how their data are utilized in the healthcare 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 non-consensual re-purposing 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 (CDC) End The Epidemic (ETE) Plan and calls for the abolition of molecular HIV surveillance in the United States as it is currently being rolled out by the CDC because it blurs the boundaries between consent and criminalisation.

Instead, we envision a future of new participatory and intersectional racial and viral justice possibilities, one which ensures the lives, voices, self-determination 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, a 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 that have led us here. Instead, we call for participatory and community-located, intersectional, racial and viral justice approaches to respond to HIV.
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> The first letter in HIV stands for Human; HIV molecules are connected to people, people who live in the social world, with rights and dignity. We look forward to further advancing the actualization of HIV data justice, where HIV responses are owned by communities, and where consent and autonomy are central.
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> In 1983, people living with HIV stood in front of medical professionals in Denver and stated:
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> > 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!

Edwin J. Bernard is executive director of the HIV Justice Network. This article was originally published on HIVJustice.net.

Like or follow HIV Justice Network on Facebook to watch and participate in the first of their new interactive webshows. Titled “HIV Justice Live! Whose Blood is it, Anyway?” and taking place live on September 30, this show will focus on molecular HIV surveillance.

For more on this topic, click here to read “Questioning the Benefits of Molecular Surveillance” from the July/August 2020 issue of POZ.

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