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We Are People, Not Clusters!

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As advocates and scholars, including people living with HIV, we have been engaged in a critical debate over molecular HIV surveillance (MHS), as well as its antecedent and future practices. We have elaborated our concerns on the ethical implications and potential harms MHS poses to our communities, in academic fora (Bernard et al. 2007; Chung et al. 2019; Dawson et al. 2020; Gilbert et al. 2016; McClelland et al. 2019; Nelson 2020), as public education initiatives (Legacy Project 2019; Sero Project 2020), in the media (Kempner 2019; Nelson 2020), and as protests (Artavia 2019). The critique of MHS has similarly been advanced by other scholars and activists concerned by the ethical challenges it poses (Benbow and Evans 2017; Coltart et al. 2018; Gilbert et al. 2016; Mutenherwa et al. 2019; Sandset 2020).

Aligned with our critique and resistance, we welcome the interrogation of MHS via the bioethics lens developed by Molldrem and Smith (2020), which provides an opportunity for a wider-ranging dialogue on bio-informational self-determination and “HIV data justice.” The authors discuss cases that crystalize three key concerns revolving around MHS, including: (1) the non-consensual re-purposing of personal health information and biomaterial for public health surveillance; (2) the enrollment of MHS data into a larger data assemblage to make determinations about transmission directionality, and the criminalizing implications that follow such determinations; and (3) the amplified targeting and stigmatization of our communities, whom are already oppressed and marginalized. In this editorial, we advance each of these concerns, calling for a critique of MHS that moves beyond the bounds of bioethics, and the arguments of MHS itself. Rather, we call for the abolition of objectifying practices such as MHS. Instead we see 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.

BEYOND BIOETHICS

We value this vital conversation brought forth by Molldrem and Smith, but we also push beyond a bioethics frame and the issue of MHS itself, moving beyond the solitary support or concern raised in many of the Open Peer Commentaries in this issue. We want to illuminate this bioethics debate over MHS by locating it within its broader context in order to make sense of why people and communities are so concerned about MHS. To address the limits of bioethics, López (2004) and Petersen (2013) have called for the field to be informed by greater detailed empirical qualitative inquiry with people. This means moving beyond the moral dilemmas presented by MHS, to address the material worlds of people and communities who may be impacted by the potential harms of the practice. It is certain that MHS has engendered resistance, but we need to understand this resistance as part of a broader refusal of our objectification.

OVERLAPPING PANDEMICS: COVID-19, HIV & CRIMINALIZATION

We write now in the midst of complex social contexts of overlapping global pandemics to argue that our current situation redoubles the urgency of the call for “HIV data justice” (Molldrem and Smith 2020). The CDC has said that MHS is focused on tracking molecules, and clusters, not people (CDC 2018). However, as Molldrem and Smith (2020) note, MHS happens not only in a sterile laboratory, but also in the complex social worlds of people. The social context in which MHS takes place today remains one where the U.S. continues to be a leading country in the world for criminalizing people living with HIV (Cameron and Bernard 2019), as well as, migration, sex work, drug use, and poverty. Additionally, we question the utility of the knowledge garnered from the MHS method, and the logic of intervention derived from the technology. We have known for years that effective

responses to HIV involve harm reduction approaches, housing, poverty reduction, accessible healthcare, and enabling environments free from criminalization, stigma and discrimination. What is needed to overturn these structural inequalities is political will, not shiny new technology.

MHS takes place in a number of different institutional realms. It is conducted by epidemiologists as part of HIV surveillance *research* as well as a central aspect of HIV public health surveillance *practice*. Surveillance is not just a matter of counting data, it has always been part of government interventions in people's lives, even in its foundations (Fairchild et al. 2007). Further, these interventions exist within the U.S. context, one that has a long history of differential legal treatment based on race, gender and sexuality (Holloway 2011). This multi-purpose use of MHS blurs boundaries and activates arguments regarding consent and criminalization. In the context of MHS solely for research purposes, it may indeed be the case that anonymity is guaranteed. However, the goal of MHS for public health surveillance is altogether different. Arguments (Wertheim et al. 2019) claiming the anonymity of study subjects is protected (we call them *subjects* as they have not willingly consented as *participants*) are undone when brought into the realm of local public health practice, which often involves identifying and intervening with people.

Furthermore, if it is believed that directionality can eventually be conclusively proven through further refinement of phylogenetic analysis, this will surely be taken up within an institutional public health assemblage that regards people living with HIV only as objects of study or targets of intervention. This is even more concerning when public health collaborates with police (Hanssens 2015; Hoppe 2013; McClelland 2019). Practices of MHS must be situated in an understanding of the historical and ongoing ways in which data about certain communities have been weaponized in racist, classist, xenophobic, misogynistic, homophobic, and/or transphobic ways to oppress, control, criminalize and punish.

Echoing the ongoing criminalization of HIV, COVID-19 has begun to be criminalized. While the two diseases are vastly different, COVID-19 criminalization has similarities to the ways which people living with HIV have historically been cast, by police and the criminal justice system, as an inherent risk to society, and as potentially dangerous perpetrators who must be identified, listed, monitored, controlled and punished (HIV Justice Worldwide, 2020; McClelland 2019). Furthermore, our ongoing work on the policing of communicable diseases has demonstrated that racialized and classed patterns of public health approaches rely on coercive police enforcement (Deshman et al. 2020, Community Resource Hub 2020).

While we are deeply concerned about the ways in which COVID-19 responses have ramped-up invasive and coercive forms of surveillance, exemplified by

data-flows from public health to police, we take hope from the creative forms of resistance to the over-policing of our communities. We are in an unprecedented anti-racist social uprising led by the powerful Black Lives Matter movement that has brought forth a mainstream interrogation of policing as an institution of structural violence, one which continues to threaten the lives of Black, Indigenous, and immigrant people, and other people of color. The vision and leadership of this Black-led social uprising means that collectively, as a society, we are implored to see beyond current forms of structural violence and oppression. This is also an opportunity to see beyond the forms of public health that have instantiated MHS as a key pillar of the response to HIV and other communicable conditions.

TOWARD ABOLITION OF HARMFUL PUBLIC HEALTH PRACTICES

While this debate on MHS is vital to our lives, and those we work with, we need a vision beyond the potential harms of the practice, to interrogate the ways of thinking and doing that got us here in the first place. In other venues, we have collectively elaborated how MHS data gathered without consent could be used to criminalize our communities, and those we work with (Chung et al. 2019; McClelland et al. 2019). When raising such concerns, we have been told by practitioners of MHS: “the public good of HIV surveillance justifies” the practice, which includes the denial of our rights to consent and autonomy over the uses of own data and biomaterial (Wertheim et al. 2019). Such responses, which commonly underpin the logic of MHS research, along with the practices of public health actors more generally, deny people living with HIV access to the rights guaranteed to the “public.” What MHS practitioners are saying to us when they appeal to the “public good” is that people living with HIV are not understood as the “public” in public health research or surveillance (Kinsman 2018). Rather, people living with HIV are regarded as a threat from whom some imaginary public is to be protected, an object to be studied from afar.

Objectification underpins many aspects of public health research and surveillance, and has persisted since the entire project of “Public Health” was initiated. This is the same logic that led to grotesque violations of the rights of Black men and their families in Tuskegee. This is the same logic that led to the use of Henrietta Lacks' biomaterial without her consent for medical study and immense profit with zero reparations to this day (Holloway 2011).

People living with HIV have resisted their objectification by medical researchers and public health institutions since the beginning of the AIDS pandemic. As authors of this editorial, our ongoing work is deeply rooted in those past historical struggles for collective rights and

autonomy. In 1983, at an American health conference, a group of people living with AIDS, wrote an historic manifesto reclaiming rights to: self-determination, participation in decision-making at all levels that affected their lives, access to healthcare, death with dignity, and being seen and treated as whole people, not just as a person with a disease. Known as the Denver Principles (1983), this manifesto also demanded the right:

To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.

What MHS demonstrates is that we are still fighting to access self-determination and informed decision-making about our lives. But this is more than an issue of violating consent (however egregious) or the specific practices of MHS. This is about undoing the objectifying, othering logic of public health actors and medical researchers. We must work toward the abolition of such logic which views the bodies and blood of people living with HIV—especially those who are Black, Indigenous and immigrant people and other people of color; people who use drugs, people who sell sex; trans women; and gay men—as objects to be studied without consent under the justification of the “public good.”

We must abolish the logic which considers non-consensual violations against our bodies and our communities as collateral damage, and not as harms done to the public.

BIO-INFORMATIONAL SELF-DETERMINATION

Data is not benign. This is true of the data and biomaterial collected for MHS. When placed in social contexts of ongoing institutional violence and racism, data can be weaponized to pathologize, target, regulate, and control (D’Ignazio and Klein 2020; Dencik et al. 2019; Milner 2020; Taylor and Kukutai 2016). Grounding their analysis in the growing movement for data justice, Molldrem and Smith (2020) note the approach, “foregrounds social justice concerns and ongoing historical struggles against inequality, oppression, and domination” (11). Groups such as Data for Black Lives, along with initiatives such as the Indigenous OCAP principles (Ownership, Control, Access, and Possession), have demonstrated how communities are mobilizing to reclaim their rights to informational self-determination, and to control how data about their lives is collected, stored, and mobilized. Similarly, movements resisting facial recognition, and those identifying embedded algorithmic biases, and others, such as #NoTechForICE, have resisted technological determinism and the harms of pervasive surveillance. We align ourselves with these movements in staking a claim on our own bio-informational self-determination.

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. 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. 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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