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To cite this article: Farirai Mutenherwa , Douglas Wassenaar & Tulio de Oliveira (2020) Adding a Voice to the Unique Ethical Considerations in Molecular HIV Surveillance, The American Journal of Bioethics, 20:10, 34-36, DOI: [10.1080/15265161.2020.1806399](https://doi.org/10.1080/15265161.2020.1806399)

To link to this article: <https://doi.org/10.1080/15265161.2020.1806399>



Published online: 18 Sep 2020.



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## Adding a Voice to the Unique Ethical Considerations in Molecular HIV Surveillance

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Moldrem and Smith (2020) provide an excellent discussion of ethical issues associated with the use of HIV genetic sequence data in molecular HIV surveillance (MHS), in particular, the complex issues that arise from the repurposing of HIV genetic testing from clinical care to a tool for HIV epidemiological surveillance and cluster detection and response (CDR). The authors achieve this objective in three steps: First, they provide a historical overview of MHS; second, they include a discussion of their theoretical framework, which is situated within the broad field of critical bioethics; and third, they present three case studies, which illuminate emerging bioethical and practical issues associated with the reuse of HIV genetic sequence data for both research and public health purposes. The first case study highlights the ethics of HIV molecular research and surveillance based on a review of available literature. In the second and third case studies, the authors draw attention to differences in opinion about the use of HIV phylogenetics to determine the directionality of HIV transmission and a myriad of ethical challenges that arose from a controversial study that used MHS to draw conclusions about transgender women.

The authors observe that, based on the available evidence, claims made by some experts that phylogenetic analysis alone cannot prove beyond reasonable doubt that person A infected person B are spurious. The authors argue, correctly in our view, that questions about whether HIV molecular data can be used to infer whether person A infected person B “miss the mark” and may not be relevant in the context of public health. We would add that conflicting statements

from experts on whether directionality of transmission can be determined, should not be treated in isolation. Rather, they should be understood within the broad methodological limitations of HIV phylogenetics as a scientific tool (Mutenherwa et al. 2019a). How the tool is applied in different contexts to answer specific questions is also important.

The methodological strengths, limitations, and pitfalls of HIV phylogenetics are an important ethical consideration, which should not be minimized to preserve the impression of scientific certainty. The scientific community and key stakeholders (people living with HIV, scientists, public health practitioners, and legal practitioners, among others) need to be fully informed about what MHS can and cannot do and what is unknown about the tool. Any gaps in information, whether intended or not, provide fertile ground for manipulation. This makes inclusive and honest engagement between key stakeholders imperative so that common ground can be established. The controversy surrounding molecular HIV surveillance and transgender women (Ragonnet-Cronin et al. 2019) gives further credence to a renewed hope for consensus building, whereby different stakeholders in the fight against HIV treat each other as partners focused on eliminating the virus, rather than as adversaries competing for turf.

In their discussion of ethical considerations, the authors suggest some tools and approaches that could be applied to reform and improve MHS and other reuses of HIV genetic sequences for public health. A key recommendation from the authors is that HIV data justice should be rooted in a strong evidence base, including

empirical research on the benefits of MHS and CDR. Such studies could assess the impact of the public health interventions and how best they could be applied ethically. Indeed, the body of evidence on the public health impact of molecular HIV surveillance remains inconclusive. Elsewhere, concerns have also been raised about whether the repurposing of HIV genetic sequences to public health surveillance provides any additional information beyond what can be established using other conventional and nonmolecular techniques (Chung et al. 2019). However, the debate is ongoing and remains inconclusive. Strong evidence of potential benefits and risks of the technology is vital to justify resource allocation for MHS versus other competing and traditional methods of inquiry (Sandset 2020).

In addition to questions about public health benefits, gaps exist in the literature on other practical, ethical, legal, social, and behavioral aspects of MHS. Several of these issues have been covered extensively by an interdisciplinary working group (Dawson et al. 2020), which was established to explore the ethical challenges in HIV-phylogenetics research conducted in the United States. There is a compelling need to foreground social and behavioral research as a critical component in the application of MHS or any other scientific innovation designed for public health purposes. Research efforts to establish how much the public understands the science, attitudes, misconceptions, and concerns should be supported and strengthened. Furthermore, there is a need to understand how to communicate with individuals and communities about results from HIV phylogenetic analysis and the impact and implications of such findings on their lives (Mutenherwa et al. 2019b). The framing of messages about the tool should be sensitively designed in contexts in which vulnerable identifiable population groups have traditionally been stigmatized as HIV carriers. Needless to say, new models of consent and mechanisms that allow people living with HIV to exercise control over the use of their genetic data (as suggested by the authors) would benefit more from empirical bioethics research and other forms of inquiry. Considering the unique characteristics that HIV phylogenetic data possess, and the circumstances under which the data are used beyond HIV clinical care, an adaptation of consent models from other contexts may not be sufficient without supporting evidence.

Context matters. In the United States and Canada (Poon et al. 2016; Ragonnet-Cronin et al. 2019) and in Europe (González-Alba et al. 2011), molecular HIV surveillance is quite common and is in many ways recognized as a critical step toward achieving zero new infections. As HIV genetic sequencing becomes

increasingly affordable, its use in HIV surveillance could extend beyond the borders of high-income countries to low- and middle-income countries (LMICs). Granted that the distinction between research and public health surveillance remains largely blurred (Sherman and Campione-Piccardo 2007), the ethical issues highlighted by the authors may assume greater importance in those environments due to weaker health systems, poor research regulatory frameworks, and in some jurisdictions a disregard for human rights. While the repurposing of HIV genetic data from clinical usage to HIV surveillance provides a useful platform for targeting prevention and care programs, it may perpetuate and amplify stigmatization of already stigmatized subpopulations if data are not analyzed and reported carefully.

The packaging of molecular HIV surveillance messages should be informed by the social, economic, and political context of people living with HIV, in particular the recognition of the intersection between HIV transmission risk and the structural-level concerns in public health. By its nature, HIV phylogenetics focuses on individual behavioral determinants of HIV acquisition and transmission and thus tends to focus on the role of the vector (people infected with HIV) rather than the pathogen (HIV) and other structural level factors (culture, poverty, stigmatization, etc.) (Sandset 2020). Structural factors may play an even greater role in fueling HIV transmission, but addressing structural drivers is quite complex despite the potential public health benefits.

## CONCLUSION

We applaud the authors for drawing attention to the ethical pitfalls that emerge from the repurposing of HIV genetic testing from clinical care to HIV surveillance. Although molecular HIV surveillance is a powerful surveillance tool, its usage and potential pitfalls (intended or otherwise) should continuously be questioned. We hope that the presentation of the ethical issues and recommendations proposed by Mollidrem and Smith for achieving HIV data justice will advance the research agenda on the repurposing of HIV molecular data from clinical care to HIV surveillance. Indeed, a dialogical approach to reform and improve MHS and related public health interventions that utilize this technology is inevitable.

## DISCLOSURE STATEMENT

No potential conflict of interest was reported by the author(s).

## FUNDING

Dr Wassenaar is partially funded by US NIH/Fogarty awards to DRILL D43TW010131 and SARETI D43TW011240-01A1 but the opinions expressed in this paper are his own and not those of National Institutes of Health. Professor Tulio de Oliveira is funded by the National Human Genome Research Institute of the National Institutes of Health, under Award Number U24HG006941.

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THE AMERICAN JOURNAL OF BIOETHICS  
2020, VOL. 20, NO. 10, 36–39  
<https://doi.org/10.1080/15265161.2020.1806384>



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## Wise Use of Surveillance Data: Evolving HIV Policy and Emerging Considerations Regarding COVID-19

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## INTRODUCTION

Molldrem and Smith (2020) raise important questions about the use of HIV molecular surveillance data by

public health departments. A more detailed look at the history of HIV testing and reporting, as well as at the structure of existing HIV care and treatment

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