Title

Consent and criminalisation concerns over phylogenetic analysis of surveillance data - Authors' reply.

Journal

The lancet. HIV, 6(7)

ISSN

2405-4704

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Publication Date

2019-07-01

DOI

10.1016/s2352-3018(19)30142-0

Peer reviewed

Consent and criminalisation concerns over phylogenetic analysis of surveillance data

As scholars and advocates, including people living with HIV, we are responding to the publication of Ragonnet-Cronin and colleagues' phylogenetic analysis in Los Angeles County (CA, USA)[1] to express our concern about a problematic turn in HIV surveillance research. Activists, legal experts, and social scientists are increasingly concerned about the rights, consent, and privacy implications of "molecular surveillance", which risks reducing people living with HIV to vectors of disease. A seemingly benign focus on molecules, with data repurposed from routine care, used secondarily without patient consent, and cross-referenced with other data sources, allows for laboratory identification of sexual HIV transmission networks. Did these women consent to their health data being used in this manner? The study positions transgender women at the centre of high-risk sexual networks; a particular concern in the USA, where there is heightened criminalisation of sex work, migration, drug use, and HIV. Although phylogenetic analysis cannot, and should not, be used to try and prove transmission directionality, it has been used to criminalise people, and to intervene in their lives, with serious consequences. Not only are the study results already known to transgender women and other experts working on the ground—that their sexual networks are different from men who have sex with men—the myriad of reasons why transgender women may be out of reach of public health authorities (eg, discrimination from health-care workers, by choice, fears of criminalisation) are also overlooked by the authors.

We declare no competing interests.

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1 Ragonnet-Cronin M, Hu YW, Morris SR, Sheng Z, Poortinga K, Wertheim JO. HIV transmission networks among transgender women in Los Angeles County, CA, USA: a phylogenetic analysis of surveillance data. *Lancet HIV* 2019; **6:** e164–72.

Authors' reply

We appreciate the opportunity to broaden the discussion of HIV surveillance. Our study analysed de-identified data collected under the auspices of public-health surveillance. When individuals are diagnosed with HIV in the USA, pertinent data, including viral genetic sequences, are reported to public-health departments. These data are protected by statute to guard individual confidentiality. HIV surveillance—which includes data collection, analysis, and interpretation—is integral to improving and allocating services for people living with and at-risk of HIV.[1] This approach helps public-health officials improve services for groups disproportionately affected by HIV, such as transgender women.

To ask whether individuals in our analysis consented to their data being used to identify HIV transmission clusters begs the question of whether consent is imperative to HIV surveillance. Surveillance for numerous infectious agents, including HIV, is done ethically and without consent.[2] The public good of HIV surveillance justifies this approach. Requiring consent for surveillance reporting would preclude a robust understanding of disease distribution and spread and the ensuing benefit to the health of individuals and communities.

The ethics of HIV surveillance have been debated long before studies of HIV genetic transmission networks, partly because some data (eg, diagnosis date and named sexual partners) have potential use in criminal prosecution. Our study was approved by university and public-health department institutional review boards. Although California recently modernised its HIV criminalisation laws,[3] these laws do vary by geography. Furthermore, we acknowledge that viral genetic analysis carries heightened risks and concomitant ethical burden. Thus, we take part in ongoing discussions of ethics with scientists, public-health officials, legal experts, and community members.[4,5]

Our study quantified the population-level relation between transgender women and people reporting other risk factors in HIV transmission clusters. To clarify, we neither put forth claims about the sexual networks of transgender women nor about their position at the centre of these networks. We did, however, detail how genetic analysis can be used to direct public-health services to transgender women by prioritising their cisgender genetic partners.[6] Molecular epidemiology can play a part in bringing an end to the HIV epidemic,[1] and it can be used ethically in a public health framework.

JOW receives funding from the Centers for Disease Control and Prevention and Gilead Sciences through grants and contracts awarded to the University of California, San Diego. We declare no other competing interests.

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Estimating fiscal space for health: pitfalls and solutions

Authors' response

We appreciate Olivier Sterck's examination of our analysis[1] and thank him in particular for extolling our estimates as a public good useful for researchers and policy makers alike; however, several critiques of our analysis were made that we believe are misinterpretations of our stated aims.

Sterck's first concern is that our potential government spending estimates were "not compared with the amount that countries would actually need to pay to efficiently confront the HIV/AIDS epidemic". For the benchmark proposed by Sterck to be relevant, one must assume that HIV/AIDS programmes can be efficiently scaled up to confront the HIV/AIDS epidemic. However, Stover and colleagues' analysis of resources needed—which was used in both our and Sterck's analyses—humbly admits their estimates include "significant uncertainty" and do not capture the real-life inefficiencies associated with the scaling up of HIV/AIDS programmes.[2] Further, Stover and colleagues put forth estimates of the annual resources needed to keep pace with a scale-up schedule that meets global goals. If countries have the available resources to confront the HIV/AIDS epidemic sooner rather than later, there is no reason for them to be tied to the schedule proposed by Stover and colleagues. For these two reasons, we feel it would be limiting to constrain our estimates of potential spending using Stover and colleagues' estimated resource needs. Presenting what governments could spend is likely more useful to decision makers as they face the reality of scaling up HIV/AIDS programmes and are operating with some inefficiencies. Second, not comparing our estimates against existing benchmarks does not bias the results; it is merely a choice made when determining how to report our estimates. Our estimates report what we believe governments could spend on HIV/AIDS and purposefully avoid thorny issues surrounding measurement of what countries should spend.

Sterck's second concern centres on variable selection for our models, assuming we are operating from the perspective of governments, that seemingly control tax policy, resource allocation across sectors and within the health sector. This assumption leads him to suggest we should not have included covariates such as the level of the health budget, overall government budget, or current economic growth as governments have control over these inputs. On the contrary, we adopted for our analysis the more focused perspective of a ministry of health. We stated explicitly that we "estimate the potential for governments to spend additional resources on HIV/AIDS, relative to their fixed health budget and other public finance, economic, and contextual factors". Because ministries of health typically have little control over the magnitude of their budget, tax revenue, or economic growth, Sterck's first rule of covariate selection suggests that these variables should be included in the analysis, as we have.

Sterck's third rule of covariate inclusion suggests that contextual variables should be included within the analysis. Following this rule, we included HIV/AIDS mortality and incidence in our modelling, as these covariates highlight critical contextual factors when pondering the amount of resources to spend on the epidemic. Although we agree with Sterck that including these variables could lead to endogeneity, we believe the endogeneity was minimal, as it is commonly thought that investments in health impact health outcomes with some time lag,[3] because programmes take time to be implemented and scaled up and to have measurable health impacts. If this is the case, the inclusion of contemporaneous HIV/AIDS mortality and incidence would not significantly bias our results.

We fully agree with Sterck and his assessment that, taken together, inclusion of the wide array of covariates offers a conservative estimate of potential spending. As presented in the supplementary appendix and stated in our discussion, "our estimates are on average less than 50% of previous estimates". This indicates that our estimates are on the conservative end, which we feel is prudent and responsible.

Lastly, Sterck suggests that quantile regressions could be an alternative to the stochastic frontier analysis (SFA) method used in our analysis. We agree that use of quantile regressions is a promising advance but believe the method requires more vetting for it to displace SFA as a dominant method in efficiency analyses. More guidance is needed in the selection of which quantile to estimate the regressions at (eg, 75%, 80%, or 95%), and the ramifications of this selection

Published **Online** April 25, 2019 http://dx.doi.org/10.1016/S2352-3018(19)30132-8

See **Online/Comment** http://dx.doi.org/10.1016/S2352-3018(19)30131-6