Drama in the Correspondence Section of The Lancet

When communities bring up concerns about research, can we expect researchers to listen and engage us? Or are we just widgets to study?

August 2, 2019 By Andrew Spieldenner, PhD

I am giving over this space to my colleague Sandra Wesley, the Executive Director of Stella, l'amie de Maimie. I am one of the authors of correspondence asking researchers to take into consideration issues of consent and how our communities are framed in Molecular HIV Surveillance (MHS) and research involving MHS. The researchers had a lackluster response to us. Sandra Wesley's insightful letter to them is inspiring to me. She has given permission to publish this as an open letter.

Haven't we already been clear about what meaningful engagement looks like?

The following letter (with minor edits for clarity) was sent to the authors of a study that " set out to identify transgender women and their partners in a molecular transmission network to prioritise public health activities." or, in plain language, tried to use fancy molecular tests from samples of positive HIV tests to figure out exactly who had sex with whom or who is using drugs with whom to map out "clusters" of infection. This type of research, done without anyone's consent thanks to police-like public health surveillance powers, can naturally lead to eventual uses in court to "prove" how someone acquired HIV and criminalize people for it. The fact that it focuses on trans women also can be quite harmful, as it does not address actual lived realities of trans women and related issues of stigma and oppression. I'm pretty sure the trans community in L.A. didn't approach those researchers asking them to do this. This massive violation of privacy yielded information only public health academics could ever find shocking or new: trans women like to fuck each other and otherwise are in contact with a lot of heterosexual cis men, who may have sex with several trans women. I have yet to receive a response from the researchers in question. Maybe they need more emails from community members and concerned colleagues? These are the email addresses to do so: jwertheim@ucsd.edu or manonragonnet@imperial.ac.uk

Hi Joel, Sheldon and Manon (author's note: I'm using first names as a power move since I know academics and physicians can be really fragile about their titles),

I am the director of Stella, l'amie de Maimie, an organization by and for sex workers located in Montreal, Canada, and also co-president of Montreal's Fast-Track Cities project. As I browsed the

most recent correspondence section in The Lancet HIV, I read the very thoughtful letter on consent and criminalisation issues linked to your study involving phylogenetic surveillance of trans women living with HIV in Los Angeles. Despite my better judgement, I clicked on your response hoping to see you being grateful for the free education and eager to address those concerns. I was then very disappointed to read your actual response and felt compelled to tell you about it.

You and your team had a great opportunity to stop and hear the message being sent to you by people directly impacted by oversurveillance and overpolicing, but you chose to defensively fall back on research ethics committees (which have a long history of fucking over marginalized people and seeing us as inert subjects as opposed to stakeholders who should direct research) and on public health surveillance models. I shouldn't have to tell you that the very notion of « public health » and its institutions is rooted in protecting the « public » from us vectors of disease. As a sex worker, this history is written into every experience I have with the state, but perhaps to you it's not so evident?

Your responsibility as a researcher goes beyond what the law and ethics committees allow you to do. You have a responsibility to consult meaningfully with the community impacted by your work, to make sure their needs are at the center of anything you publish even if it means not being able to do the cool, fun project you want to do, even if that project feels like it has a lot of potential to help people. For many of us, mitigating risks of surveillance and criminalisation is way more important to our survival than reducing HIV infections or any other public health goal.

A group of people took the time to let you know that your work might impact marginalized people, especially trans women, negatively. You responded by dismissing them and refusing to do the work necessary to respect the actual human beings whose lives you have some power over. In French, we have a word for people who make careers on the backs of people living with HIV without being accountable: « Sidacratie » (mix of aids and aristocracy if you're fancy or bureaucracy if you're just following orders). It's up to you to decide if that's who you want to be or if you want to actually improve lives.

I hope you will publish a better response than the garbage I read this afternoon in The Lancet.

Sincerely,

Sandra Wesley

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