Transparency, HIV Stigma And Accountability

March 21, 2013 By Todd Heywood

LANSING - The conversation went something like this:

“You mean you would report my HIV status?” the man asked.

“If it was relevant to the story, yes, yes I would,” I told him.

The man stared at me in disbelief. “You can’t do that. I don’t want anyone to know I am HIV positive,” he said. Yet, he was appointed to a public body to represent people living with HIV in determining how the state would spend federal HIV dollars in addressing the epidemic in Michigan.

I was attending the Michigan HIV/AIDS Council meeting on March 14, and at issue was a required confidentiality agreement. The agreement had to be signed to attend the public meeting of a public body - a big no-no under Michigan’s Open Meetings Act.

But the principle of confidentiality in relation to disclosing a person’s HIV status is, in fact, an important part of addressing HIV in the state. So this incident led me, in conversation with my editors at The American Independent and Between The Lines, to ask “shouldn’t we be transparent about how we determine to disclose or not disclose the name of a person living with HIV?” And, of course, we should.

Disclosure of an HIV status is a serious concern with implications going beyond the instant moment and can impact employment, relationships and civil rights. I know, because I am living with HIV. Many activists say that one incredibly important tool in fighting stigma and discrimination is for those living with HIV to be out about their status. However, that decision has to be - except in very rare, narrowly defined situations - a personal decision.

So how do we as news agencies go about reporting a person’s HIV status in a news story?

It is essential to understand that generally, reporting on someone’s HIV status will be predicated on their permission. In many instances, if someone’s status is important to the story, but disclosure could negatively impact that person, I will offer anonymity to the person. That decision is reached after discussions with both the subject, editors and sometimes with ethics experts.

As an ethical rule, we will not identify, by name, individuals charged under various HIV disclosure, exposure and transmission laws. Why?

First, as the Poynter Institute has told us in phone interviews, it is unethical to identify the alleged perpetrator and not the alleged victim in a case that is predicated on an act, usually sexual, that is

consensual. Either both are named or neither will be named. It’s that simple.

Secondly, in multiple instances, police have charged a suspect under various state laws, naming that person as HIV-positive. But further review finds that the person is, in fact, not living with HIV. That disclosure, once made, cannot be taken back in this world of online permanence, and can lead to significant negative impacts on a person who is presumed to be living with HIV. It’s unfair, it’s unethical and we won’t do that.

Thirdly, in these cases, if the accused is willing to talk to us on the record and disclose his or her status, with his or her name attached, we will report that person’s name. We have in the past reported the stories of those living with HIV who admit to breaking a state disclosure law, but we have not identified them. Why? Because the story they have to tell about stigma and how it impacts their thinking in relation to disclosure is more important than the identity of the person - and identifying the person could lead to them facing criminal charges.

The media is not, and never should be, an arm of the police. It is not our job to help police embark on witch hunts to find additional alleged victims of HIV-specific crimes. The police can do that all on their own with a bevy of legal powers at their discretion.

Ultimately, we embark on very difficult conversations every day about when, if and how to identify those living with HIV, or those alleged to be living with HIV. We very carefully weigh the public’s right to know with the privacy of the person living with HIV. It is not an easy balancing act to perform, but it is essential to reporting about HIV in the United States and assuring our sources that we respect and value their privacy. These are just examples of the process we undergo as we evaluate reporting, and how we determine who to identify and when. We believe we regularly strike a solid balance between those conflicts of privacy and public policy, and drive for transparency on the public policy issue, not the details of whether or not a person is living with HIV.

This article was originally published on Between the Lines.

© 2026 Smart + Strong All Rights Reserved.