



NO DATA NO MORE

Manifesto to Align HIV Prevention Research with Trans and Gender-Diverse Realities

PREAMBLE

From the Co-Authors

As a trans woman who is masculine-attracted, it often pains me to see how women like me (who have sexual and intimate relations with cis-het men, masculine gay men, trans men, and masculine-identified and -presenting women) are often ignored in research and programs because of presumptions about our bodies and lives.

Trans and gender-diverse persons construct, experience and express our various identities in nuanced ways. For example, trans women may identify as lesbians, and some trans men are gay or men who have sex with men (MSM). Some trans people prefer intimate partnerships with each other. There are also pansexual and gender nonbinary people, in addition to heteronormative and binary-identified trans people. For these nuances to be visible in data sets, it's important for trans-identified people to be on the forefront of research done about and for us—"nothing without us."

Trans-diverse communities have far too often experienced a lack of leadership and participation in compulsive binary and cis-heteronormative research and programming. Subsequently, our health outcomes and rights are further challenged—hence the need for this manifesto.

—Tshepo Ricki Kgositau, Cape Town

Based on who I am—a transmasculine person who has sex with cis men—I fall under two of the five designated WHO key populations (KP) that are most at risk for HIV. Yet my identity as a person placed in high-risk sexual networks is historically and consistently overlooked by the HIV establishment. Transmasculine and other assigned female at birth (AFAB) trans people have been neglected in HIV research and care for decades. Many of us identify as MSM. Some are sex workers; others inject drugs or represent a constellation of several KPs at once. Yet AFAB trans people are still not recognized enough by researchers and health care providers to investigate the specific risks to our community or to offer us medically appropriate and accessible care. If we aren't being discriminated against or even attacked, I and my community live with missing knowledge on the side of doctors or a lack of information based on insufficient research. One might better understand now why we often shy away from medical help, even when we need it. Or, why trans people are more often living with HIV and our general health status is comparably poor. The status quo is a burden to us as individuals and an impediment to the movement's attempt to control HIV. This is the reason we drafted this manifesto.

—Max Appenroth, Cologne

My years of working with, and for, the transgender movement at sub-regional and Pan-African levels have allowed me to appreciate and elevate diversity within trans communities. As a manager of trans-focused HIV programs on the African continent, I can testify to trans people lamenting a lack of appropriate and specific HIV prevention commodities and amenities due a lack of trans representation at decision-making tables. As a queer woman who has sexually intimate relations with transmasculine beings, transmen and masculine-expressing lesbian women—among the various masculine expressions I am attracted to—I have seen how programmers miss very significant HIV vulnerabilities of masculine and trans nonbinary persons' prevention needs.

Developing this manifesto has been an opportunity to inform and direct future research and advocacy around HIV prevention science for trans and gender diverse (TGD) persons. For trans-focused programs to be effective, trans people—who recognize the subtleties and nuances that often go overlooked—need to be in the leadership seat, informing in-depth analyses and recommendations to ultimately shift the way research informs policy and programs. This is the objective of this manifesto.

—Immaculate Nyawira Mugo, Cape Town

Around the world, we need HIV research that is accurate, comprehensive and free of the very stigma and biases that are at the heart of the decades-long HIV pandemic. Yet the majority of research protocols, articles and conference presentations still speak of "men" and "women", as if these binary designations include all people at risk of, or living with, HIV. This language and conduct are not only inaccurate—they risk the very integrity of HIV research itself and perpetuate the marginalization of trans and gender-diverse people. This will not be corrected by simply adding the word "cisgender" or extending research based on the assumption that trans people are in the "wrong bodies" or all seeking to emulate binary lives. It's far past time to put trans and gender diverse researchers and community members in positions of power in trial design, prioritization, funding and analysis. We don't need to waste any more time getting this wrong, as lives depend on it.

—JD Davids, Brooklyn