



U.S. PLHIV
CAUCUS



POSITIVE WOMEN'S NETWORK
USA

SERO+



WHITMAN-WALKER
Institute

October 17, 2023

Dr. Jonathan Mermin, Director
National Center for HIV, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
Washington, DC 20510

Dr. Robyn Neblett Fanfair, Director
Division of HIV Prevention
National Center for HIV, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
Washington, DC 20510

Dear Directors Mermin and Fanfair,

We, the undersigned HIV prevention, care and advocacy organizations, respectfully request that key officials in the Centers for Disease Control and Prevention (CDC) National Center for HIV, Viral Hepatitis, STD, and TB Prevention meet and meaningfully collaborate with the US People Living with HIV Caucus before the next iteration of Molecular HIV Surveillance and Cluster Detection and Response (MHS/CDR) policies.

We write this letter on the one-year anniversary of the Presidential Advisory Council on HIV/AIDS (PACHA) MHS/CDR Resolution as a part of our commitment to a key principle that has guided the HIV movement for 40 years: the Meaningful Involvement of People living with HIV/AIDS (MIPA).¹ Our demand for MIPA is informed by the US People Living with HIV Caucus' vision of MIPA in a modern U.S. context:

...true MIPA must account for regional differences as well as intentionally developing and supporting leaders living with HIV from marginalized communities, especially Black and Latinx people, youth, people who use drugs, immigrants, the LGBTQ community, cisgender and transgender women, people with incarceration experience, sex workers, people aging with HIV, and so many others. There is no "one-size-fits-all" model to assure meaningful engagement of community, and it takes time for government and public health partners to build trust with communities that have been harmed by multiple systems. Through real and ongoing partnership with organized, constituency-led formations that reflect most impacted communities, like PLHIV networks, these nuances can be addressed over time.²

¹ UNAIDS, *The Denver Principles* (1983)

https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf.

² U.S. People Living with HIV Caucus, *Demanding Better: An HIV Federal Policy Agenda by People Living with HIV* (2021) pg. 10, <https://www.pwn-usa.org/wp-content/uploads/2021/07/Networks-Policy-Agenda-FINAL.pdf>.

We write this letter with the clear understanding that those who are closest to the problem are closest to the solution. The bodies, sexuality, reproduction, and movement of communities most affected by HIV, especially LGBTQ+ and Black, Indigenous and People of Color communities, have been controlled and policed since before the HIV epidemic in the U.S.. Today, those same communities are disproportionately harmed by long-standing and emergent regressive policies that compromise their fundamental rights.

1. There has been insufficient MIPA in the visioning, policy-making, planning, implementation, and evaluation of MHS/CDR policies.

In January 2018, the CDC released PS18-1802, a five-year funding cycle that mandated the adoption of molecular surveillance technologies by health departments as a condition for HIV prevention funding.³ No networks of people living with HIV (“PLHIV networks”⁴) in the U.S. were meaningfully consulted prior to this expansion. The vast majority of the MHS-related “community engagement” sponsored by the CDC of which we are aware took place after the implementation of PS 18-1802. While PLHIV networks and human rights advocates have raised serious concerns about potential incursions on patient privacy, lack of informed consent, collateral legal and material consequences arising from HIV stigma and criminalization, and the investment of resources in MHS that might have been better allocated to address racial inequities in the HIV response, CDC has made insufficient progress in adopting concrete policy changes to address these documented concerns.

The basic tenet of MIPA requires engaging with the impacted community, not informing them of decisions made after the fact. Engaging the community requires embracing models of shared leadership. Informing the community is comparatively passive and exemplifies a troubling approach by which agencies and power-holders make program determinations *prior* to consultation with directly impacted constituencies and then aim to get the community on board *afterward*.⁵

Similarly, not all “stakeholders” are equal. A meeting with public health officials, HIV advocacy organizations, or even workers at community health centers is not a community meeting unless people living with HIV, especially from those communities who are most impacted by HIV—and in this case, dually by policing and surveillance—have a formal policy making seat at the table, not just tokenistic representation. This is what we refer to as “structural MIPA.” Meetings with “stakeholders” that do not meet this basic principle of structural MIPA are insufficient to fulfill the CDC’s obligation for community engagement.

³ Centers for Disease Control and Prevention (CDC), *Funding opportunity announcement (FOA) PS18-1802: Integrated human immunodeficiency virus (HIV) surveillance and prevention programs for health departments* (2017) <https://www.cdc.gov/hiv/funding/announcements/ps18-1802/index.html>.

⁴ PLHIV networks are organized formations created, led by, and accountable to the estimated 1.2 million people living with HIV (PLHIV) in the United States. PLHIV networks are vehicles through which people living with HIV can define their agenda, choose their leaders, and speak with a collective voice. PLHIV networks in the US represent communities most impacted by the epidemic in the United States: Black gay and bisexual men living with HIV in the U.S. South, Black cisgender and transgender women living with HIV, transgender women of color living with HIV, Latinx people living with HIV, survivors of HIV criminalization, and people aging with HIV. See, U.S. People Living with HIV Caucus, *Demanding Better: An HIV Federal Policy Agenda by People Living with HIV* (2021), <https://www.pwn-usa.org/wp-content/uploads/2021/07/Networks-Policy-Agenda-FINAL.pdf>.

⁵ Spieldenner, A. R., French, M., Ray, V., Minalga, B., Sardina, C., Suttle, R., Castro-Bojorquez, M., Lewis, O & Sprague, L., “The Meaningful Involvement of People with HIV/AIDS (MIPA): The participatory praxis approach to community engagement on HIV surveillance,” *Journal of Community Engagement and Scholarship*, 14(2), Article 1. Available at: <https://jces.ua.edu/articles/10.54656/jces.v14i2.26>.

We acknowledge and appreciate the CDC, Divisions of HIV and STD Prevention's Listening Tour in southern U.S. cities that is currently underway.⁶ When people living with HIV are effectively involved in policy development, implementation and monitoring, our public health strategies improve. Public forums, if intentionally structured to prioritize the representation and expertise of constituencies that are directly and disproportionately affected by HIV, are one way to create space for the involvement of people living with HIV in the federal HIV response.

There is not, however, a "one-size-fits-all" model to assure meaningful engagement of community. Listening sessions do not include active, ongoing involvement in policy development, implementation and monitoring over time, nor do they often have robust opportunities for dialogue and feedback from the policy makers in the room. There is a marked difference between taking input from individuals living with HIV and engaging with organized PLHIV networks. Processes to take input from individuals living with HIV generally have no available mechanisms for, nor resources to support, community accountability. Nor do they provide real avenues to support engagement by people living with HIV representing the communities most affected by HIV, who may face various barriers that circumscribe their ability to effectively participate in decision-making or advisory processes.

PLHIV Networks, HIV and human rights organizations, coalitions, and other bodies have given the CDC roadmaps for how to address concerns with concrete policy change. Exactly one year ago PACHA unanimously approved a resolution to address human rights and data privacy and security concerns about the ongoing and expanding reliance on MHS/CDR.⁷ PACHA's MHS/CDR Resolution substantially overlaps with the recommendations made previously by other groups that advocate with and/or for people living with HIV, including the US People Living with HIV Caucus,⁸ the AIDS United Public Policy Council,⁹ and HIV Justice Worldwide.¹⁰ To date, most of these recommendations have not been meaningfully adopted.

We call for real and ongoing partnership with organized, constituency-led formations that reflect most impacted communities, including the US People Living with HIV Caucus.¹¹ Involving PLHIV networks in decision-making and implementation translates into concrete benefits for public health programs; prioritizing community trust, cultural humility, and lived experience facilitates

⁶ Southern AIDS Coalition, "Coming to you: CDC Listening Tour" (2023), <https://southernaidscoalition.org/cdc-listening-tour/>.

⁷ Presidential Advisory Council on HIV/AIDS (PACHA), *Molecular HIV Surveillance and Cluster Detection and Response Resolution* (2022), <https://files.hiv.gov/s3fs-public/2022-11/PACHA-resolution-on-Molecular-HIV-Surveillance-Cluster-Detection-and-Response-10-17-22.pdf>.

⁸ U.S. People Living with HIV Caucus, *Demanding Better: An HIV Federal Policy Agenda by People Living with HIV* (2021), <https://www.pwn-usa.org/wp-content/uploads/2021/07/Networks-Policy-Agenda-FINAL.pdf>.

⁹ AIDS United Public Policy Council, *Position Statement on the use of Molecular Surveillance to Track HIV Transmission Networks* (2020), <https://www.hivlawandpolicy.org/sites/default/files/AIDS%20United%20Molecular%20Surveillance%20Statement.pdf>. AIDS United Public Policy Council, *CDC NOFO Process & Priorities Recommendations* (2022), <https://drive.google.com/file/d/14PRDAEQWPZjCMUzsypSMND5VWGpppaZl/view>.

¹⁰ Positive Women's Network-USA & HIV Justice Worldwide, *Molecular HIV Surveillance: A Global Review of Human Rights Implications Briefing Paper* (2021), <https://www.hivjusticeworldwide.org/wp-content/uploads/2021/10/HJWW-MHS-Paper-English-Final.pdf>.

¹¹ The United States People Living with HIV Caucus (the HIV Caucus) emerged in 2010 from the need for a national voice for PLHIV. The HIV Caucus is composed of members Global Network of People Living with AIDS -- North America, International Community of Women with HIV/AIDS -- North America, National Working Positive Coalition, Positively Trans, Positive Women's Network-USA (PWN), Reunion Project, SERO Project, and THRIVE SS. As a national "network of networks," the HIV Caucus has taken the lead on several issues that PLHIV face, including addressing national HIV plans and policies that most affect people living with HIV in the U.S.

the development and implementation of strong programs that are more likely to achieve their public health goals.

2. The ongoing mistrust of the health system by people living with HIV is grounded in historic failures by public health institutions and exacerbated by ongoing failures, undermining public health goals to “end the HIV epidemic.”

Although the USPHS Tuskegee Syphilis Study¹² is often held up as the “most egregious” example of malfeasance committed by government health officials in the name of scientific discovery and public health, it is not the only such example and mistrust of the medical establishment due to racism, queerphobia, and HIV stigma in contemporary policies and practice continues to fester.¹³ Much of our health system has only recently begun to reckon with the impact that racism, homophobia, and transphobia have had on our medical theories and science.¹⁴ Trust in our health systems is further eroded by contemporary and emergent policies aimed at criminalizing health and healthcare, including but not limited to HIV, abortion, and gender-affirming care.

The legitimate fear that one’s personal health data could be used against them in the course of seeking healthcare is antithetical to public health goals, including the goals stated in the “Ending the HIV Epidemic Plan” and yet is rampant in our current political environment. A 2022 study found that 45% of criminal cases for allegedly self-managing abortion came to the attention of law enforcement through healthcare providers.¹⁵ This year, news broke that Vanderbilt University Medical Center in Tennessee—a state that now actively criminalizes gender-affirming care for minors—turned over patient records from its pediatric transgender clinic to the state’s Attorney General.¹⁶

As the federal government works to better protect the private medical information of people who can become pregnant,¹⁷ CDC must also work with PLHIV networks as necessary partners to help organize, inform, and implement data privacy and protection policies in relation to HIV surveillance technology, such as MHS/CDR. The active obfuscation of MHS/CDR’s existence and policies by the CDC only serves to further heighten mistrust of the medical system, and inclination to not engage in care, by people living with HIV.

3. The CDC must meet and actively collaborate with the US People Living with HIV Caucus before the iteration of MHS/CDR policies.

“The effectiveness of institutions depends heavily on the public’s trust.”¹⁸ Issues such as the mistrust caused by MHS require the CDC to refer back to its guiding principles, found in the Principles of the Ethical Practice of Health (quoted in the previous sentence) and its Pledge to

¹² CDC, The U.S. Public Health Service Syphilis Study at Tuskegee, <https://www.cdc.gov/tuskegee/timeline.htm>

¹³ Washington, H.A., *Medical Apartheid*, Doubleday, New York, NY (2006).

¹⁴ For example, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9495470/>.

¹⁵ Laura Huss, Farah Diaz-Tello, & Goleen Samari, *Self-Care, Criminalized: August 2022 Preliminary Findings* (August 2022), <https://www.ifwhenhow.org/resources/self-care-criminalized-preliminary-findings/>.

¹⁶ Skipworth, William, “Vanderbilt Hospital Turns Over Transgender Clinic Records To GOP Attorney General In Investigation,” *Forbes* (2023); Hodgman, Lucy, “Tennessee ban on gender-affirming care for minors to go into effect for now,” *Politico* (2023), <https://www.politico.com/news/2023/07/08/tennessee-gender-affirming-care-ban-00105308>.

¹⁷ National Archives, “HIPAA Privacy Rule To Support Reproductive Health Care Privacy,” *Federal Register* (2023), <https://www.federalregister.gov/documents/2023/04/17/2023-07517/hipaa-privacy-rule-to-support-reproductive-health-care-privacy>.

¹⁸ Public Health Leadership Society, *Principles of the Ethical Practice of Public Health* (2022), https://www.apha.org/-/media/files/pdf/membergroups/ethics/ethics_brochure.ashx.

the American People. The solution to ending the epidemic, as the CDC has committed to do, does not solely rely on having the best science or scientific knowledge. It demands the active collaboration and buy-in of PLHIV Networks, working as partners not as “consumers,” “clusters,” “vectors of disease,” or “people who are underserved.”

By engaging in Molecular HIV Surveillance under a veil of secrecy and without true MIPA, the CDC is ignoring the lessons of the past—about the debilitating and ongoing impact of breaches of trust between government health officials and the people they serve—to the detriment of the public health that it is sworn to promote. And this is while PLHIV Networks make clarion calls of their concerns, echoed by federal bodies such as PACHA.

With the expiration of PS 18-1802, the CDC has an opportunity to remediate the problematic lack of MIPA and address human rights violations posed by the implementation of MHS/CDR in the next iteration of MHS/CDR policies. In the end, it is simple: take the steps necessary to truly engage with and listen to the concerns of people living with HIV or continue to allow the rift between the CDC and the public trust to expand, moving us further away from ending the HIV epidemic. The first step is to meet and actively collaborate with the US People Living with HIV Caucus, as the “network of networks” of people living with HIV, before the next iteration of MHS/CDR policies.

For more information or question, please contact:

Ronald Johnson

Chair
US People Living with HIV Caucus
Rjohn0403@aol.com

Kamaria Laffrey

Co-Executive Director
Sero Project
kamaria.laffrey@seroproject.com

Naina Khanna

Co-Executive Director
Positive Women’s Network-USA
Naina@pwn-usa.org

Amir Sadeghi

Policy and Advocacy Manager
Center for HIV Law and Policy
amir@hivlawandpolicy.org

Benjamin Brooks

Associate Director of Policy and Education
Whitman-Walker Institute
BBrooks@whitman-walker.org

Kelly Flannery

Policy Director
Positive Women’s Network-USA
kelly@pwn-usa.org

This letter has been endorsed by the following organizations:

Advocates for Youth
AIDS Action Baltimore
AIDS Alabama
AIDS Alabama South
AIDS Foundation Chicago
AIDS United
All Under One Roof LGBT Advocates of SE Idaho
Alyssa Rodriguez Center for Gender Justice
American Academy of HIV Medicine (AAHIVM)

APLA Health
Appalachian Learning Initiative
Arkansas RAPPS
AVAC
Best Practices Policy Project
Black & Pink National
Blanc Slate Firm
Caracole, Inc.
Cascade AIDS Project
Center for Health Law and Policy Innovation (CHLPI)
Central Illinois Friends
CHANGE New Orleans
Chicago Women's AIDS Project
CHLP
Colorado Organizations and Individuals Responding to HIV/AIDS (CORA)
Community Solutions
Contigo Fund
Desiree Alliance
Equality Federation
Family Service of Greater Baton Rouge
Five Horizons Health Services
Freedom Oklahoma
Frontline Legal Services
Galaei
Garden State Equality
Georgia Equality
GMHC
GoodWorks: North AL Harm Reduction
Health Not Prisons Collective
Health and Education Alternatives for Teens (H.E.A.T.), SUNY Downstate
HIV Modernization Movement-Indiana
HOPE Cape Town USA
Horizon Ridge Wellness Clinic, Inc.
Idaho Coalition For HIV Health and Safety
International Community of Women Living with HIV
Just B U Inc.
Lambda Legal
Legacy Community Health
Legal Action Center
Lilmesican Productions, Inc. - A Social Enterprise
Louisiana AIDS Advocacy Network
Louisiana Coalition on Criminalization and Health
Michael Reese Research and Education Foundation
Minority Health Consultants

Movimiento en Respuesta al VIH Inc.
NAESM, Inc.
National Alliance for HIV Education and Workforce Development (NAHEWD)
National Harm Reduction Coalition
National Working Positive Coalition
New Haven Mayor's Task Force on AIDS
New Orleans Advocates for LGBTQ+ Elders (NOAGE)
NEW Pride Agenda
National HIV and Aging Advocacy Network (NHAAN)
NMAC
North Carolina AIDS Action Network (NCAAN)
Ohio Health Modernization Movement
OnePULSE Foundation, Inc.
PA-HIV Justice Alliance
Positive People Network Inc.
Positive Women's Network-New York chapter
Positive Women's Network-Pennsylvania chapter
Positive Women's Network-South Carolina chapter
Positive Women's Network-USA
Positively U
Proactive Community Services
QLatinx
Rural Women's Health Project
SAGE
San Francisco AIDS Foundation
SEEDS of Healing, Inc.
Sero Project
SOMOS LOUD, Central FL Chapter
Strategies for High Impact
Southern AIDS Coalition
SWOP Behind Bars
T2Q Trans Quantum Questioning LLC
Tennessee HIV Modernization Coalition
The Black Cave
The Bros in Convo Initiative
The Counter Narrative Project (CNP)
The New Pride Agenda
The Reunion Project
The Sankofa HIV Initiative
The Well Project
Thrive Alabama
THRIVE SS, Inc
Transgender Law Center
Transgender Legal Defense & Education Fund

TransProgram
Treatment Action Group
Unique & Unified New Era Youth Movement
Unity Fellowship of Christ Church NYC
US People Living with HIV Caucus
Vivent Health
VOCAL-NY
We the Positive / My Brother's Keeper
Western North Carolina AIDS Project
Whitman-Walker Institute
William Way LGBT Community Center
Woman to Woman We Are One
Women With A Vision