

The Consensus Statement on HIV Bodily Autonomy, Surveillance, and Informed Consent (BASIC)

HIV BASIC is a group of advocates, including people living with HIV (PLHIV), abolitionists, researchers, racial justice and human rights organizers, and public health policy and legal experts working together to address the crisis connecting health status criminalization, public health, and the ever-broadening erosion of privacy and bodily autonomy in the United States. This statement establishes shared principles and commitments for an HIV response grounded in bodily autonomy, informed consent, and freedom from criminalization.

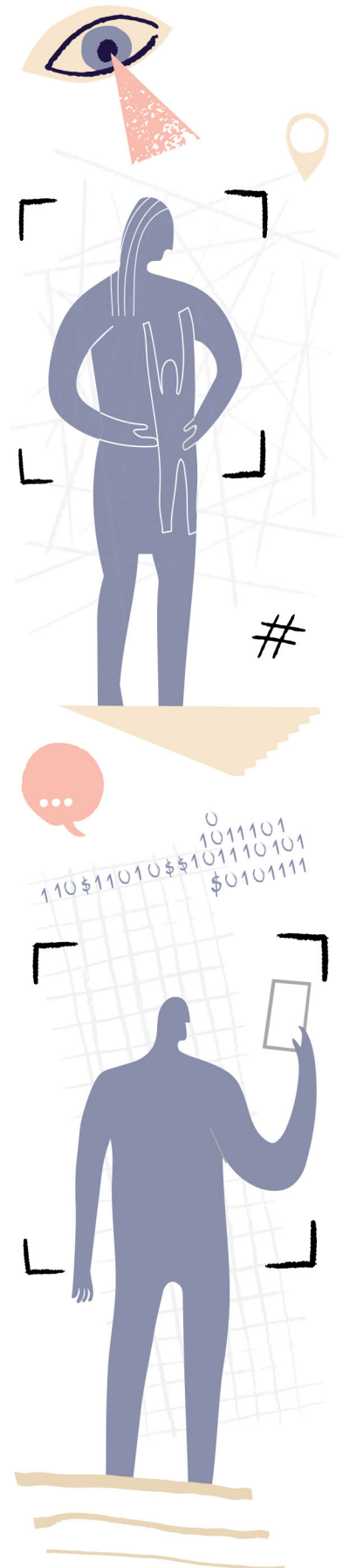
Discrimination and bias based on race, sexuality, gender, class, and disability have underpinned public health institutions and practices for centuries, including the HIV response. Ever since the beginning of the epidemic, researchers, public health practitioners, and policymakers have bypassed and suppressed the fundamental rights of PLHIV. Historically, many of these same stakeholders have played a role, either through their cooperation or their refusal to resist, in the criminalization of health status and the collection, analysis, storage, and distribution of sensitive health data beyond what is strictly necessary, without sufficient regard for the informed consent or privacy rights of PLHIV.

Bodily autonomy, surveillance, informed consent, and privacy are deeply interconnected. They form the foundation that dictates whether an individual has a right to self-determination over their own body and personal data. **Bodily autonomy** is the fundamental right to make decisions about one's own body and life without external interference. **Informed consent** acts as the required ethical and legal mechanism to ensure that any action affecting a person's body is done with their full understanding and explicit permission. **Privacy** provides the necessary protective space for exercising bodily autonomy.

Public health surveillance can be a tool to analyze, interpret, and respond to the transmission of diseases and health inequities on a population level. However, surveillance systems and practices are not neutral, apolitical, or value-free.¹ The implementation of public health surveillance exists within medical exploitation and violence,² racialized and gendered state power, and bias in data practices. Furthermore, vague and inconsistent state laws and regulations govern how data is shared. Some states have explicit legal frameworks permitting the disclosure of sensitive information to courts and law enforcement. Monitoring and collecting data without appropriate safeguards erodes privacy, undermines autonomy, and violates the trust of all patients, particularly those who experience legacies of mistreatment, racism, and discrimination, jeopardizing the integrity of the public health infrastructure.

1 Ryan J. Petteway, Daniel López-Cevallos, Mira Mohsini, Andres Lopez, Roberta S. Hunte, Tim Holbert, and Kusuma Madamala. "Engaging Antiracist And Decolonial Praxis TFootnoteo Advance Equity In Oregon Public Health Surveillance Practices." Health Affairs Vol. 43, No. 6: 813-831 (2024), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2024.00051>.

2 "How History Has Shaped Racial and Ethnic Health Disparities: A Timeline of Policies and Events." KFF, <https://www.kff.org/racial-equity-and-health-policy/how-history-has-shaped-racial-and-ethnic-health-disparities-a-timeline-of-policies-and-events/?entry=1808-to-1890-medical-exploitation-of-enslaved-black-women>.



If surveillance is not built on the core principles of informed consent, bodily autonomy, and sufficient privacy protections, it increases the risk that people's private information will be publicly exposed or used against them. Those risks perpetuate fear and mistrust. Thus, these real dangers directly threaten the entire public health ecosystem by undermining trust from the people that system serves.

The national public health infrastructure is already collapsing. Racist disparities in HIV incidence continue. Medical data are shared and weaponized against people receiving gender-affirming and reproductive care. HIV-related arrests and prosecutions are keeping pace or even increasing across the country. Tens of thousands of people are being detained and disappeared in broad daylight, driving fear in immigrant communities and pushing them further away from medical services. Funding streams are running dry. States are beginning to reckon with this grim reality, proposing cuts to the ability to access HIV treatment, impacting thousands. It is necessary to respond to these interconnected crises and completely envision a framework for ending not only the epidemic, but all inequities in health outcomes across the board.

The undersigned agree...

1. The Meaningful Involvement of People Living with HIV (MIPA) is critical to a just, equitable, and effective HIV response.

- Policymaking on HIV at all levels, including the creation of health data confidentiality procedures, legislation, rules and regulations, HIV testing guidelines, and beyond, cannot proceed without the meaningful inclusion of PLHIV. It is fundamental to center PLHIV and establish leadership among PLHIV so they have input before decisions are adopted on HIV and public health policies at the municipal, county, state, and federal levels that affect PLHIV, their data, and how those data are shared or used.
- Leadership, input, and meaningful guidance on HIV policymaking must go beyond exclusively engaging HIV planning groups that do not represent the communities most policed and criminalized. True MIPA integrates a lens around racial, gender, class, ability, and other axes of power and privilege. This must include the representation of leaders living with HIV from targeted communities, especially Black and brown PLHIV, trans and gender-diverse people, women and femmes living with HIV, sex workers living with HIV, immigrants affected by HIV, and PLHIV who use drugs, and people who have been incarcerated. The establishment of listening sessions does not meet this standard when it is not immediately transparent how the input from PLHIV who are most impacted is integrated into the decisions that shape HIV testing, public health, and health data confidentiality policy.
- Institutional Review Boards (IRBs) examining the ethical implications and ultimate approval of scientific research involving and affecting PLHIV, such as research or public health analysis relying on the collected medical data from PLHIV, must also involve PLHIV who are representative of the communities most stigmatized and policed.

2. Informed consent is foundational to building trust in healthcare systems.

- The right to be meaningfully and accurately informed about what health information is being collected from PLHIV, who will have access to that information, and how that information will be used, including secondary analysis or use for public health purposes, can never be overlooked. This is central to the mission of building a public health infrastructure worthy of trust.
- People have the right to decide when, if, and how they are tested for a stigmatized and criminalized health condition. Any scheme to screen people without directly engaging and notifying them beforehand infringes on the core premise that makes opt-out HIV testing a meaningful balance between the positive public health outcomes of increased testing and people's informed consent rights. Opt-out testing as a framework only works when people consent and can thereby decide against being tested or discuss health outcomes and the importance of sexual health literacy with their provider(s). Similarly, any scheme to test people nonconsensually (e.g., against their will or in a way that is not administered without meaningful, direct notification beforehand) jeopardizes the goal of building trust with marginalized communities.

3. Health data must only be used for health purposes.

- The risks of public health surveillance data being accessed by law enforcement and immigration enforcement, as determined by federal and state laws, must be clearly communicated to all patients. Additionally, other data privacy risks, including the harms that data breaches and inadequate security standards pose to marginalized communities, must be directly communicated to patients when they engage in care.

- Public health officials, healthcare providers, and policymakers responsible for how our medical and public health data systems are designed must work with PLHIV to understand the issues with the inconsistent and porous borders surrounding sensitive health information and take action to implement secure safeguards to prevent any health information from ever being released to law enforcement or used in criminal, administrative, or civil legal proceedings.

4. Bodily autonomy includes data autonomy.

- All people, including all PLHIV, have the right to decide and refuse how their medical data, including information obtained through the course of their direct care, is collected, stored, analyzed, and used for public health purposes. Attempts to discern information about the social, sexual, and drug-using relationships of PLHIV, however well-intended, depend on collecting and using data that many would not willingly disclose when the risks associated with this surveillance are openly discussed with them.
- PLHIV have the right to make informed, impactful decisions free from influence, coercion, and misrepresentation about our bodies, products of our bodies, and the data collected from us used for public health purposes.

5. Bodily autonomy includes freedom from state control, surveillance, and policing.

- Marginalized and policed communities, including but not limited to PLHIV, should not have to choose between maintaining our privacy and accessing the essential health services we need to stay alive.
- Public health surveillance, when conducted in a fashion that does not center the bodily autonomy rights of marginalized communities and/or implemented with disregard for the risks concerning how data can be weaponized against us, violates the trust of the people most affected by stigmatized diseases and health conditions. Public health cannot work without the collection, use, and analysis of data, but neither will it work without public trust. That trust must be earned by addressing the harms of state violence and the role medical and public health officials have played in the criminalization of gender-affirming care, reproductive health care, diseases, substance use, and other health statuses.

6. Policing and criminalization are antithetical to the health and sustainability of our communities.

- Criminalization, including the arrest, prosecution, and imprisonment of people based on their health status, is illegitimate and incompatible with our vision of liberatory public health. Liberatory public health can and should be concerned with protecting communities from harm, including systemic oppression and state violence, and ensuring people have the resources, services, and whole care needed for them to thrive. In addition to exposing people to racist discrimination, violence, and incarceration, health status criminalization deepens medical mistrust and pushes our most marginalized communities away from the testing, education, treatment, and care that make public health functional.
- Public health practitioners and medical professionals require education on how the United States criminal legal system functions to manage inequality, and its criminal laws are selectively enforced on marginalized communities. Those working in public health and medicine have a crucial role and ethical imperative to play in minimizing their participation in and support for policing and criminalization of the marginalized people they serve.

These principles and standards represent the minimum conditions for a just HIV response that addresses our crumbling public health environment, rising inequality, unacceptable health inequities, and escalating state violence. Earning trust from policed and criminalized communities requires a firm and unambiguous commitment to meaningful joint partnership across HIV policymakers, care providers, public health practitioners, and people with direct, lived experience of criminalization and health care divestment.

**Endorse the Consensus Statement on HIV BASIC
at tinyurl.com/hiv-basic**



Organizations and Individuals endorsing the Consensus Statement on HIV BASIC

Endorsements as of July 8, 2026.

ORGANIZATIONS (153)

A New PATH (Parents for Addiction Treatment & Healing)	Equitas Health	NASTAD
Abortion Care Network	Evolve Tampa Bay	National Black Harm Reduction Network (NBHRN)
ACCESS Reproductive Justice	Ex Aequo - Belgium	National Family Planning & Reproductive Health Association
Advance Maryland	Faith in Harm Reduction	National Harm Reduction Coalition
Advocates for Trans Equality	Freedom Oklahoma	National Native American AIDS Prevention Center (NNAAPC)
Advocates for Youth	FreeState Justice	National Organization for Women
AIDS and Rights Alliance for Southern Africa	Georgia Equality	National Working Positive Coalition
Alameda County Drug User Health Advisory Committee (DUHAC)	Ginger Lee Global Health Consulting Group	Naxos Neighbors, LLC
Alaskan AIDS Assistance Association	GLAAD	NBJC
All Under One Roof of Southeastern Idaho	GLMA: Health Professionals Advancing LGBTQ+ Equality	NC AIDS Action Network
American Academy of HIV Medicine (AAHIVM)	Harm Reduction Sisters	NEW Pride Agenda
American Academy of HIV Medicine (AAHIVM) Community Advisory Group (CAG)	Hawai'i Health & Harm Reduction Center	New Unity -Fellowship of Christ Church-NY
Aniz Incorporated	Health Justice	New York Doctors Coalition/Health Justice for New York
APAIT	Health Not Prisons Collective	Next Generation Men of Transition
Arkansas Black Gay Men's Forum	Healthy and Free Tennessee	NMAC
Association of Nurses in AIDS Care	HISTORI: HIV Implementation Science to Optimize Research Impact	Ohio Equal Rights
Autistic Women & Nonbinary Network	HIV & AIDS Legal Clinic Ontario (HALCO)	Ohio Health Modernization Movement
Balanced Imperfection	HIV i-Base	Our WORK Supportive Housing Program
Beurre Roux	HIV Justice Network	P.O.W.E.R. Atlanta, Inc. (Protecting Our Wellness, Equality & Resources)
Birthmark	HIV Modernization Movement - Indiana	PHREEDOM
Black South Rising	Hondurans Against AIDS	Plus Life Media
brighter NC (bNC)	HOPICS	Positive Iowans Taking Charge
California LGBTQ Health and Human Services Network	House of gg: Griffin Gracy Educational Retreat & Historical Center	Positive People Network, Inc.
Center for Health Law and Policy Innovation (CHLPI)	Ibis Reproductive Health	Positive Women's Network-NYS Chapter
Center on Reproductive Rights and Justice at the University of California Berkeley Law	Idaho Coalition for HIV Health and Safety	Positive Women's Network-PA Chapter
Centre for Social Research in Health; Social Policy Research Centre, UNSW Australia	If/When/How: Lawyering for Reproductive Justice	Positive Women's Network-USA
Centre for Women Justice Uganda	Illinois Commission on LGBTQ+ Aging and Long-Term HIV Survival	PRC San Francisco
CHLP	InclusHIV Consulting	Presbyterian HIV Network, PHEWA, PC USA
Circles Of Solidarity	interACT	Prism Health North Texas
Colorado Organizations and Individuals Responding to HIV/AIDS (CORA)	International Community of Women Living with HIV North America	Project Pink'd Elephant
Dandelion, Inc.	Just Futures Collaborative	Punks with Lunch Lansing
Decriminalize Sex Work	Lambda Legal	Red Ribbon Foundation (SA)
Desiree Alliance	Lawyers for Good Government	Restorative Action Alliance
Details at XI Media - Detroit	Legal Action Center	Ribbon-A Center of Excellence
Drug Policy Alliance	Louisiana Coalition on Criminalization and Health (LCCH)	Safe Space Fort Smith
Electronic Privacy Information Center	Love Me Unlimited 4Life/ForeverCaring	San Francisco AIDS Foundation
Equality California	Evonne	Santa Clara County Drug User Health Advisory Committee (SCC-DUHAC)
Equality New Mexico	LOVEboldly	SERES
Equality Ohio	Mama+ Health Policy Group	Sero Project
	Missouri HIV Justice Coalition	Shri Radheykrishna Oaj (AIDS Vaccine) Organisation
	Mpact Global	SIECUS: Sex Ed for Social Change

Silver State Equality
 SisterReach, Inc. and SisterReach Illinois
 Skipalis Training & Consultation
 Smoke Lilies Jade
 Soul Soil Healing
 Southern AIDS Coalition (SAC)
 Southern Nevada Health Consortium
 St. Ann's Corner of Harm Reduction
 The 6:52 Project Foundation, Inc.
 The Black Feminist Reproductive Justice,
 Equity & HIV/AIDS Activism (BREHA)
 Collective
 The Counter Narrative Project (CNP)
 The Porchlight Collective SAP

The Project of the Quad Cities
 The Reunion Project
 The Strilite Foundation, Inc.
 The Transgender Cultural District
 The TransLatin@ Coalition
 The Well Project
 Trans Equity Consulting
 Transgender Education Network of Texas
 (TENT)
 Transgender Law Center
 Triad Health Project
 U.S. People Living with HIV Caucus
 Uganda Young Positives (UYYP)
 Under the Umbrella RGV

Unitarian Universalists for a Just Economic
 Community's Healthcare Task Force
 Unity Fellowship of Christ Church NYC
 VOCAL-NY
 We the Positive Network
 Women of Valor
 Women With A Vision
 Women's Health & Evolutionary Wellness
 Woodhull Freedom Foundation

INDIVIDUALS (182)

Emily Abrahams	Fernando De Hoyos	Alonda Hutchinson Hall	Rena McCain	Khosrow Sadeghi
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Justin Almodovar	Denise Drayton	Heather Jackson	Montemayor Morales	Cristine Sardina
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Rownoka Ashakhan	Maria Ekstrand	Anthony Johnson	Kim Moon	Karl Schmid
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Lydia Babcock	Etienne	Keddrick Jones	Kenya Moussa	Chance Shaw
Ed Baker	Sarah Feldman	Dr. Evonne Kaho	Jaime Mueller	B.C. Skipalis
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Annie Johnson Benifield	Carrie Foote	Victoria Kirby York	Warren O'Meara-Dates	LaDawn Tate
Gretchen Bergman	Kris Ford	Sarah Komugisha	Gabriella Olague	Ronnie Taylor
Jannah Bierens	Myra Franks	Peggy Korpela	Sheila Ombongi	Andy Tinoco
Margaret Bordeaux	Maddy Frey	Roger Lacoy	Michelle Orengo-	Jerry Tobe
Wanda Brendle-Moss	Adriana Galdo Adams	Kamaria Laffrey	McFarlane	Rose Todd-Stanford
Gail Brown	Denford Galloway	Elnora Lawrence	Jeffery Parks	Alecia Tramel-McIntyre
Reginald Brown	Fiona Galvin	Isaiah Lawrence	Andrew James Paterson	Carla Treloar
Larry Bryant	Tracie Gardner	Nora Lawrence	Ivan Pena-Aparicio	Glyceria Tsinas
Barb Cardell	Sue Gibson	Ginger Lee	Eric Pfeider	Monique Tula
Lisa Carver	Jacqueline Goldenberg	Tamara Lester	Susan Pfretzschnr	Bandana Uniyal
Yves Chu	Alfredo González	Kevin Lish	Bridgette Picou	Steven Vargas
Chad Clarke	Manuel Gonzalez-	Carol Loomis	Valerie Pinkston	Amber Vlangas
Michaela Clayton	Carrasco	Terry Lowman	Rev. Erica Poellot	Jacob Vogel
Rebecca Cleary	PJ Gouldmann	Rachel Luce	Lee Raines	Konor von Kraut
Joanne Cogdell	Jeff Graham	Michael Luciano	Venita Ray	Kathleen Ward
Jennifer Collins	Adonis Gutierrez	Heather Lusk	Eric Reece	Laurence Wilson
Katie Collins	Carrie Hadley	Mary Maestas	Melanie Reese	Darren Wright
Simon Collins	Jacqueline Hannah	Derrick Mapp	Lis Regula	Sattie Zapata-
Nikki Cotto	Khadija Hassan	Suzanne Marks	Chris Reynolds	Nyachwaya
Joanne Csete	Tami Haught	Krista Martel	Joanna Robinson	Nyx Zierhut
Darci Curwen-Garber	Kelsea Hector	Nancy Mason	Arnetta Rogers	
JD Davids	James Hoagland	Demarcus Mathews	Michael Rouppet	
Eric Davis	Rev. Dr. Ben Huelskamp	Cole McAfee	Jessica Sadeghi	