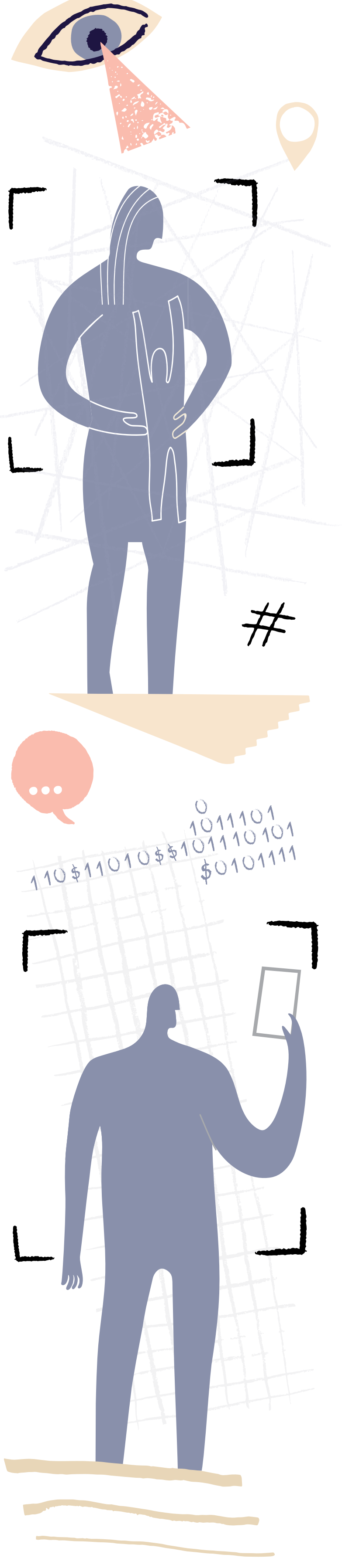
The Consensus Statement on HIV Bodily Autonomy, Surveillance, and Informed Consent (BASIC)

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 reenvision 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)
Abortion Care Network
ACCESS Reproductive Justice
Advance Maryland
Advocates for Trans Equality
Advocates for Youth
AIDS and Rights Alliance for Southern Africa
Alameda County Drug User Health Advisory Committee (DUHAC)
Alaskan AIDS Assistance Association
All Under One Roof of Southeastern Idaho
American Academy of HIV Medicine (AAHIVM)
American Academy of HIV Medicine (AAHIVM) Community Advisory Group (CAG)
Aniz Incorporated
APAIT
Arkansas Black Gay Men's Forum
Association of Nurses in AIDS Care
Autistic Women & Nonbinary Network
Balanced Imperfection
Beurre Roux
Birthmark
Black South Rising
brighter NC (bNC)
California LGBTQ Health and Human Services Network
Center for Health Law and Policy Innovation (CHLPI)
Center on Reproductive Rights and Justice at the University of California Berkeley Law
Centre for Social Research in Health; Social Policy Research Centre, UNSW Australia
Centre for Women Justice Uganda
CHLP
Circles Of Solidarity
Colorado Organizations and Individuals Responding to HIV/AIDS (CORA)
Dandelion, Inc.
Decriminalize Sex Work
Desiree Alliance
Details at XI Media - Detroit
Drug Policy Alliance
Electronic Privacy Information Center
Equality California
Equality New Mexico
Equality Ohio
Equitas Health
Evolve Tampa Bay
Ex Aequo - Belgium
Faith in Harm Reduction
Freedom Oklahoma
FreeState Justice
Georgia Equality
Ginger Lee Global Health Consulting Group
GLAAD
GLMA: Health Professionals Advancing LGBTQ+ Equality
Harm Reduction Sisters
Hawai'i Health & Harm Reduction Center
Health Justice
Health Not Prisons Collective
Healthy and Free Tennessee
HISTORI: HIV Implementation Science to Optimize Research Impact
HIV & AIDS Legal Clinic Ontario (HALCO)
HIV i-Base
HIV Justice Network
HIV Modernization Movement - Indiana
Hondurans Against AIDS
HOPICS
House of gg: Griffin Gracy Educational Retreat & Historical Center
Ibis Reproductive Health
Idaho Coalition for HIV Health and Safety
If/When/How: Lawyering for Reproductive Justice
Illinois Commission on LGBTQ+ Aging and Long-Term HIV Survival
InclusHIV Consulting
interACT
International Community of Women Living with HIV North America
Just Futures Collaborative
Lambda Legal
Lawyers for Good Government
Legal Action Center
Louisiana Coalition on Criminalization and Health (LCCH)
Love Me Unlimited 4Life/ForeverCaring Evonne
LOVEboldly
Mama+ Health Policy Group
Missouri HIV Justice Coalition
Mpact Global
NASTAD
National Black Harm Reduction Network (NBHRN)
National Family Planning & Reproductive Health Association
National Harm Reduction Coalition
National Native American AIDS Prevention Center (NNAAPC)
National Organization for Women
National Working Positive Coalition
Naxos Neighbors, LLC
NBJC
NC AIDS Action Network
NEW Pride Agenda
New Unity -Fellowship of Christ Church-NY
New York Doctors Coalition/Health Justice for New York
Next Generation Men of Transition
NMAC
Ohio Equal Rights
Ohio Health Modernization Movement
Our WORK Supportive Housing Program
P.O.W.E.R. Atlanta, Inc. (Protecting Our Wellness, Equality & Resources)
PHREEEDOM
Plus Life Media
Positive Iowans Taking Charge
Positive People Network, Inc.
Positive Women's Network-NYS Chapter
Positive Women's Network-PA Chapter
Positive Women's Network-USA
PRC San Francisco
Presbyterian HIV Nerwork, PHEWA, PC USA
Prism Health North Texas
Project Pink'd Elephant
Punks with Lunch Lansing
Red Ribbon Foundation (SA)
Restorative Action Alliance
Ribbon-A Center of Excellence
Safe Space Fort Smith
San Francisco AIDS Foundation
Santa Clara County Drug User Health Advisory Committee (SCC-DUHAC)
SERES
Sero Project
Shri Radheykrishna Oaj (AIDS Vaccine) Organisation
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 (UYP)
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
Grace Achepohl
Michael Aksten
Brent Allan
Justin Almodovar
Gabriel Aquino
Rownoka Ashakhan
Bertrand Audoin
Aaron Austin
Lydia Babcock
Ed Baker
Dorian Peter Basson
Mateo Belen
Donald M Bell
Lizzie Bellamy
Annie Johnson Benifield
Gretchen Bergman
Jannah Bierens
Margaret Bordeaux
Wanda Brendle-Moss
Gail Brown
Reginald Brown
Larry Bryant
Barb Cardell
Lisa Carver
Yves Chu
Chad Clarke
Michaela Clayton
Rebecca Cleary
Joanne Cogdell
Jennifer Collins
Katie Collins
Simon Collins
Nikki Cotto
Joanne Csete
Darci Curwen-Garber
JD Davids
Eric Davis
Fernando De Hoyos
Mike Dembski
Derek Canas
N. Dietz
Denise Drayton
Renai Edwards
Maria Ekstrand
Jessica Erves
Elder Antionettea Etienne
Sarah Feldman
Roy Ferguson
Stuart Fisk
Blake Flaugher
Elmer Flores
Carrie Foote
Kris Ford
Myra Franks
Maddy Frey
Adriana Galdo Adams
Denford Galloway
Fiona Galvin
Tracie Gardner
Sue Gibson
Jacqueline Goldenberg
Alfredo González
Manuel Gonzalez-Carrasco
PJ Gouldmann
Jeff Graham
Adonis Gutierrez
Carrie Hadley
Jacqueline Hannah
Khadija Hassan
Tami Haught
Kelsea Hector
James Hoagland
Rev. Dr. Ben Huelskamp
Alonda Hutchinson Hall
Terrwyn Hywel
Olga Irwin
Charlotte Jack
Heather Jackson
Sarah Jackson
Anthony Johnson
Maria Johnson
Vanessa Johnson
Keddrick Jones
Dr. Evonne Kaho
Althea Karwowski
Elby Kat
George Kerr III
Paul Kidd
Victoria Kirby York
Sarah Komugisha
Peggy Korpela
Roger Lacoy
Kamaria Laffrey
Elnora Lawrence
Isaiah Lawrence
Nora Lawrence
Ginger Lee
Tamara Lester
Kevin Lish
Carol Loomis
Terry Lowman
Rachel Luce
Michael Luciano
Heather Lusk
Mary Maestas
Derrick Mapp
Suzanne Marks
Krista Martel
Nancy Mason
Demarcus Mathews
Cole McAfee
Rena McCain
Brian Minalga
Mark Misrok
Samantha Rose Montemayor Morales
Susan Montford
Kim Moon
Jesus Mora
Pablo Moulden
Kenya Moussa
Jaime Mueller
Susan Mull
Jen Nagel-Fischer
Scott Nass
Isabel Nunes
Warren O'Meara-Dates
Gabriella Olague
Sheila Ombongi
Michelle Orengo-McFarlane
Jeffery Parks
Andrew James Paterson
Ivan Pena-Aparicio
Eric Pfleider
Susan Pfretzschner
Bridgette Picou
Valerie Pinkston
Rev. Erica Poellot
Lee Raines
Venita Ray
Eric Reece
Melanie Reese
Lis Regula
Chris Reynolds
Joanna Robinson
Arneta Rogers
Michael Rouppet
Jessica Sadeghi
Khosrow Sadeghi
Liz Salomon
Georgie Sanchez
Brenna Sardina
Cristine Sardina
Michael Scarce
Karl Schmid
Jordan Scott
Jordan Selha
Chance Shaw
B.C. Skipalis
Ashley Slye-Williams
Meta Smith-Davis
Liam Strausbaugh
Catherine Swanson
LaDawn Tate
Ronnie Taylor
Andy Tinoco
Jerry Tobe
Rose Todd-Stanford
Alecia Tramel-McIntyre
Carla Treloar
Glyceria Tsinas
Monique Tula
Bandana Uniyal
Steven Vargas
Amber Vlangas
Jacob Vogel
Konor von Kraut
Kathleen Ward
Laurence Wilson
Darren Wright
Sattie Zapata-Nyachwaya
Nyx Zierhut