

Show your love for People Living with HIV

Social Media Toolkit

Background

Did you know that public health officials are taking and sharing HIV viral sequence data without consent from people living with HIV? This is a practice known as molecular HIV surveillance (MHS) and cluster detection and response (CDR). We have serious concerns that our personal medical information is being used for surveillance purposes without meaningfully involving people living with HIV in program planning, without informed consent and even without our knowledge.

HIV surveillance and HIV criminalization collide to put the human rights of people living with HIV at risk, and can be especially dangerous for Black people, communities of color, sex workers, and other communities that are hyper-policed and over-surveilled.

The Centers for Disease Control and Prevention (CDC) is the primary federal agency responsible for the widespread and escalating use of MHS/CDR. We have told them time and time again that they need to make changes to respect and protect the human rights and dignity of people living with HIV. Most recently, the Presidential Advisory Council on HIV/AIDS (PACHA) unanimously passed an [historic resolution](#) that responds to our concerns and urges the CDC to change their guidance on MHS/CDR activities.

Join us in telling the CDC that they MUST implement the PACHA resolution! The human rights and dignity of people living with HIV cannot wait.

GRAPHICS

[This folder](#) contains graphics you can download and upload to your [facebook](#), [instagram](#) or [twitter](#) to accompany the social media posts below!

Hashtags

- #ILoveConsent #MyBodyMyData #CommunitiesNotClusters #EndMHS

Priority handles

- Tag: @CDCgov @CDC_HIV @dr_demetre in all your posts!
- Orgs to tag: @uspwn @hivlawandpolicy @HIVcaucus

Links

- PACHA MHS/CDR Resolution: bit.ly/PACHAresolution

Sample Posts [short]

💖 LOVE 💖 means never having to say, "I'm sorry I used your HIV genetic data without your knowledge or consent." @CDCgov @CDC_HIV @dr_demetre #ILoveConsent #MyBodyMyData #CommunitiesNotClusters bit.ly/PACHAresolution

Roses are red 🌹
Violets are blue 💙
Doctors should tell you 🩺
What they're going to do (with your data) 💣

A poem for @CDCgov @CDC_HIV listen to #PACHA bit.ly/PACHAresolution

Roses are red 🌹
MHS makes me blue 😞
Informed consent matters ✨
And #MIPA does too 💖

A poem for @CDCgov @CDC_HIV listen to #PLHIV bit.ly/PACHAresolution

.@CDCgov @CDC_HIV, show your love for people living with #HIV by listening to #PACHA!
Implement their MHS/CDR resolution today! bit.ly/PACHAresolution #ILoveConsent
#MyBodyMyData #CommunitiesNotClusters

Chocolates: \$15 🍫
Roses: \$33 🌹
Dinner for two: \$68 😊
Human rights for people living with #HIV: Priceless ✨

@CDCgov @CDC_HIV @dr_demetre, listen to #PACHA! bit.ly/PACHAresolution
#ILoveConsent #MyBodyMyData #CommunitiesNotClusters #endMHS

Sample Post [long]

I love human rights. I love informed consent. I love people living with HIV!

I'm standing up against public health officials taking and sharing HIV viral sequence data without consent from people living with HIV. This practice – known as molecular HIV surveillance (MHS) and cluster detection and response (CDR) – is deeply concerning.

>> FIRST, our personal and sensitive medical information is being used for surveillance purposes without meaningfully involving people living with HIV in program planning, without informed consent and even without our knowledge.

>> SECOND, HIV surveillance and HIV criminalization collide to put the human rights of people living with HIV at risk, and can be especially dangerous for Black people, communities of color, sex workers, and other communities that are hyper-policed and over-surveilled.

>> THIRD, the CDC could make changes to better respect and protect the human rights and dignity of people living with HIV. But they haven't!

We know the changes that need to be made. Most recently, the Presidential Advisory Council on HIV/AIDS (PACHA) unanimously passed a historic resolution that responds to these concerns and urges the CDC to change their guidance on MHS/CDR activities. (Read more about it here: <http://bit.ly/PACHAresolution>.)

Join me in telling the CDC that they MUST implement the PACHA resolution! The human rights and dignity of people living with HIV cannot wait!