



# Ending the Epidemic Requires Consent & Community Leadership

## What is the plan?

The U.S. government has committed to ending the domestic HIV epidemic in a decade. The plan, Ending the HIV Epidemic: A Plan for America ("the ETE plan"), was announced February 2019 and promised to reduce the rate of new HIV transmissions by 75% in five years and 90% in ten.

The ETE plan will direct resources into 48 target counties, Washington, D.C., San Juan, Puerto Rico, and seven states with a high rural HIV rate. The plan rests on four basic pillars:

1. Expand testing to diagnose people with HIV as early as possible.
2. Treat HIV early and rapidly to suppress the virus (because viral suppression means people with HIV can't pass on the virus - undetectable = untransmittable).
3. Scale up prevention interventions such as PrEP and syringe exchange.
4. Use surveillance data, specifically molecular HIV surveillance, which analyzes HIV genetic sequences to determine when an "outbreak" is happening and target resources to address that outbreak.

The plan asks each jurisdiction to take the lead in creating and implementing an ETE plan that is tailored to the needs of their communities.

## This sounds good. Why are advocates concerned?

Problem	What does this mean?
<b>The federal ETE plan is exclusively focused on biomedical interventions (pills and surveillance data).</b>	There is no plan to address structural and policy barriers that limit access to health care and prevention services for low-income communities and Black, indigenous, Latinx, and other people of color in the first place. Pills are not a magic solution. We still have to get them to people.
<b>There is no clear plan for meaningful community involvement in local ETE planning processes.</b>	The administration has stated that there will be community involvement but gave local authorities significant leeway to determine: 1) which stakeholders from the HIV community should be invited into the planning process, and 2) how their feedback will be incorporated. This is a problem. ETE planning processes are moving so fast that community outreach and involvement has been sorely lacking. There is no formal requirement that local planning bodies: 1) reflect and include groups most impacted by HIV in their communities, or 2) establish clear principles and procedures to ensure transparency and meaningful involvement from people living with HIV.
<b>The plan's implementation depends on molecular HIV surveillance (MHS), which poses a potential danger to people living with HIV, due to HIV stigma and the practice of HIV criminalization.</b>	Molecular HIV surveillance is the process of tracing networks of HIV transmission by using HIV genomic sequence data that is obtained when a person living with HIV gets a resistance test. Resistance tests are generally conducted when someone is first diagnosed with HIV and then at points when they are considering changing their treatment regimen. These sequences of HIV genomic information go into a national database and are then compared to each other to determine whether viruses are likely to be genetically related. If two viruses are closely related, they are considered to be in the same network of transmission (meaning they are genetically linked). When a number of viruses are found to be closely related within a short period of time, this is called a "transmission cluster." Health departments are then tasked with identifying the people involved in the transmission cluster and offering them prevention and health care services. This all sounds pretty good – but the problem is that more than 30 states have laws criminalizing HIV transmission, exposure, or non disclosure, so molecular HIV surveillance could, even unintentionally, place people with HIV at risk for prosecution. This is of particular concern for communities that already face high levels of surveillance and criminalization, independently of HIV status, including Black people, immigrant communities, other people of color, people who trade sex, people who use drugs, and people who live on the street.

# Recommendations

**1. The Centers for Disease Control and Prevention (CDC) must declare an immediate moratorium on molecular HIV surveillance until data privacy, security, and criminalization concerns are addressed.**

**Because molecular HIV surveillance places people with HIV at elevated risk for prosecution and criminalization, ETE jurisdictions should decline to participate in that part of the plan.**

- a. Questions to ask: *This is not a question. This is a demand to protect our communities.*

**2. Communities most impacted by the problem must lead the solution.**

- a. *Sample question to ask:* "How will you include the voices and leadership of [people living with HIV] in the planning and implementation process?"

PRO TIP: Demand precision and accountability with this question. Ask specifically what percentage of the planning body will be reserved for people living with HIV. Demand a breakdown also by race, gender/gender identity, and sexual orientation, and that this is written into the plan..

**3. Community coalitions formed to lead ETE planning processes must also address structural and policy barriers to foster an environment where human rights are upheld and basic needs are addressed.**

- a. *Sample questions to ask:*

- i. "I see that our state has laws criminalizing HIV, which is a barrier to people wanting to get tested or access health care once diagnosed. What will this coalition do to advocate for HIV decriminalization in our state?"
- ii. "How will our plan address structural issues that impact people living with HIV, like housing and food insecurity, employment discrimination, and lack of culturally relevant health care?"

**4. Given ongoing attacks by the Administration on access to health care and services for immigrants and transgender people, ETE plans must specifically and proactively address the needs of these communities.**

- a. *Sample questions to ask:*

- i. "The Administration is taking steps to remove protections from discrimination for transgender people accessing health care and other necessary services. What will our ETE plan do to ensure that transgender people who need services are protected from discrimination?"
- ii. "Recent policies have fostered an environment where immigrants of any legal status are afraid to access basic services they need to survive, including HIV testing and treatment."
  - A) What steps will our ETE plan take to ensure that no data on immigration status and no identifying information about people accessing services in our jurisdiction is collected or shared?
  - B) What will be required by providers funded by this ETE plan to ensure that their locations are designated as sanctuary sites so ICE cannot enter, and to create and train staff at these locations on protocols if immigration authorities seek to violate the human right to health care?"