REPORTING WITH CARE: HIV UPDATES FOR MEDIA

PROVIDED BY: POSITIVE WOMENS NETWORK

EUALITY FLORIDA

OBJECTIVES



- ▶ **Review** updates on HIV treatment and prevention as well criminalization
- **Examine** HIV stigma and its impact (stigmatizing language & biases)
- ▶ **Discuss** and **practice** inclusive, non-discriminatory language, behavior, and community outreach best practices.



INTRODUCTIONS

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HIV: WHAT'S CHANGED?



EDUCATION REDUCES DISCRIMINATION.



We need to talk about HIV--but we need to do it in a way that educates and encourages understanding. When talking or writing about HIV-related issues or people living with HIV, consider sharing some of these facts.

Share these facts:

- A person living with HIV who takes their antiretroviral medications as prescribed can reduce the amount of virus in their blood to an undetectable level, allowing them to live a normal, healthy life.
- **Undetectable=untransmittable:** a person who maintains an undetectable viral load at least 6 months *cannot transmit* the virus to sexual partners, even without condoms. (For more, see uequalsu.org)
- Though 35 states criminalize people living with HIV for consensual sexual activities, criminalization has never been shown to be effective at preventing transmission. In fact, research shows it to be counterproductive to efforts to end the epidemic, fueling stigma and discouraging testing, treatment, and disclosure.
- Success at reducing new transmissions has been achieved by improving access to care and services needed to stay in care (like housing, mental health, transportation, etc.); by engaging people living with HIV in leadership roles in efforts to end the epidemic; and by addressing factors that make people vulnerable to HIV, like poverty, racism, transphobia, homophobia, and discrimination.



Learn more at pwn-usa.org







Undetectable = Untransmittable (U=U)



- A person living with HIV, through effective treatment, can reduce the amount of virus in their body to levels where it cannot be detected in labs: this is called an "undetectable viral load." A person with an undetectable viral load may say they are "undetectable."
- A person with an undetectable viral load *cannot transmit* HIV to sexual partners, even without condoms.
- ▶ This has been proven and confirmed by numerous large-scale studies over the past decade, involving thousands of serodifferent couples (heterosexual and same-sex) and hundreds of thousands of condomless sex acts. These studies include HPTN 052 (2016), PARTNER (2016), and PARTNER 2 (2018)
- Learn more at uequalsu.org



If U=U, why isn't everyone living with HIV undetectable?



- Though U=U is wonderful news and holds tremendous promise for efforts to end the epidemic, there are still numerous obstacles in the U.S. that prevent many people living with HIV from reaching undetectable. These include:
 - Unequal access to affordable health care
 - Stigma and bias in medical provider settings, especially for LGB and trans people
 - Lack of supportive services needed to stay in care, such as housing, mental health care, transportation, etc.
 - Mass incarceration and consequential disruptions in treatment
 - Drug resistance, often in long-term survivors or those who have experienced frequent disruptions in treatment, can make it more challenging to find a treatment regimen that works



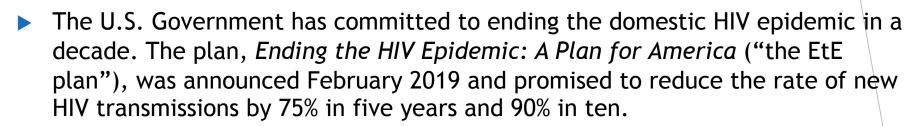
Pre-Exposure Prophylaxis (PrEP)



- ▶ PrEP is an exciting tool that prevents an HIV-negative person from acquiring HIV by taking one pill a day (99% effective).
- Many insurance plans cover PrEP, especially for people considered especially vulnerable to HIV, with low or no co-pays.
- ► However, PrEP is extremely expensive for people whose insurance plans do not cover it, or who have high co-pays or deductibles.
- ▶ Unfortunately, many doctors still do not know about PrEP (or don't know enough), and/or have biases, particularly against LGB and trans people, that prevent them from recommending or prescribing PrEP to patients who could benefit from it.



End-the-HIV-Epidemic Plans (EHE or EtE)





- ► The EtE plan will direct resources into <u>48 target counties</u>, Washington, D.C., San Juan, Puerto Rico, and seven states with a high rural HIV rate. The plan rests on <u>four basic pillars</u>:
 - Expand testing to diagnose people with HIV as early as possible
 - ► Treat HIV early and rapidly to suppress the virus (because viral suppression means people with HIV can't pass on the virus #UequalsU)
 - Scale up prevention interventions such as PrEP and syringe exchange
 - ▶ 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.



Ending the Epidemic Plan: Concerns



- While it is promising to see renewed attention to HIV from the federal government, HIV advocates have several concerns with the federal plan, including:
 - ▶ It is focused exclusively on biomedical interventions (pills and surveillance data), ignoring many of the systemic and structural barriers to prevention and care.
 - There is no clear plan for meaningful community involvement in local EtE planning processes.
 - ► The plan depends on Molecular HIV Surveillance (MHS), which poses a potential danger to people living with HIV, due to stigma and criminalization.
 - ► The government is cutting funding from agencies that is currently used to serve people living with HIV to put toward the new plan.

Learn more at pwn-usa.org/ete-factsheet-2019.



HIV STIGMA & ITS IMPACT

HIV STIGMA

EQUALITY FLORIDA

- DETERS PEOPLE FROM BEING OPEN ABOUT THEIR STATUS
- DETERS PEOPLE FROM SEEKING TESTING & TREATMENT
- SOCIAL ISOLATION
- MENTAL HEALTH ISSUES
- INTERPERSONAL RELATIONSHIPS
- ► HEALTHCARE DECISIONS & BEHAVIOR
- ► INTERNALIZED STIGMA





IMPACT OF STIGMATIZING REPORTING





- CRIMINALIZATION
- DISCLOSING PEOPLE'S STATUS
- ▶ JEOPARDIZE LIVELIHOOD
- ► SOCIAL RAMIFICATIONS
- ▶ POTENTIAL VIOLENCE
- ► PERPETUATES STEREOTYPES
- FEEDS MISINFORMATION
- **▶ INCREASE DISCRIMINATION**
- ► REINFORCE RESPONSIBILITY ON ONE SEXUAL PARTNER



SAMPLE HEADLINE





Scientists discover first new HIV strain in nearly two decades





MISLEADING & SENSATIONAL





Related Article: HIV-prevention drugs will soon be available without a prescription at California pharmacies

'There's no reason to panic or even to worry about it a little bit," Fauci said. "Not a lot of people are infected with this. This is an outlier."

For scientists to be able to declare that this was a new subtype, three cases of it must be detected independently. The first two were found in the Democratic Republic of Congo in the 1983 and 1990.

The two strains were "very unusual and didn't match other strains," Rodgers said. The third sample found in Congo was collected in 2001 as a part of a HIV viral

diversity study.

The sample was small, and while it seemed similar to the two older samples, scientists wanted to test the whole genome to be sure. At the time, there wasn't technology to determine if this was the new subtype.



CULTURAL SYSTEMIC CHANGE

- OPENLY SPEAK ABOUT HIV
- MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV
- ▶ WHAT'S THE CONTEXT?
 - SCIENTIFICALLY ACCURATE?
 - ► RELEVANT TO YOUR AUDIENCE?
 - ► EDUCATIONAL OPORTUNITY?
- ► ESTABLISH RELATIONSHIPS WITH LOCAL HIV SERVICE PROVIDERS AND NONPROFIT.
- ► GET TESTED; ENCOURAGE OTHERS
- STAY INFORMED HIGHLIGHT POSITIVE STORIES





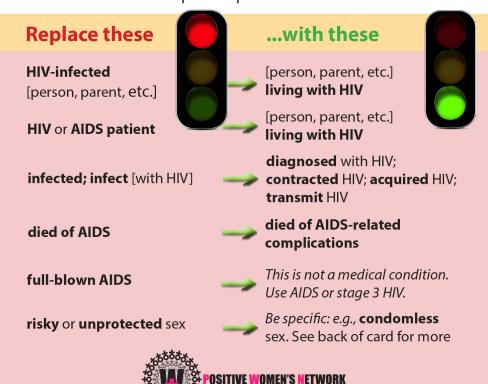


LANGUAGE MATTERS



Words have power.

We need to talk about HIV--but we need to do it in a way that protects and respects the humanity and dignity of those living with HIV. Language that implies judgment or shame fuels stigma, which kills people--and keeps the epidemic alive.





Other stigmatizing language to avoid



- Use "sex work" and "sex workers" rather than "prostitution" and "prostitutes"
- Use "person who injects drugs" rather than "drug addict"
- As a general rule, always put the person before the condition or behavior.



HIV CRIMINALIZATION

HIV-SPECIFIC LAWS



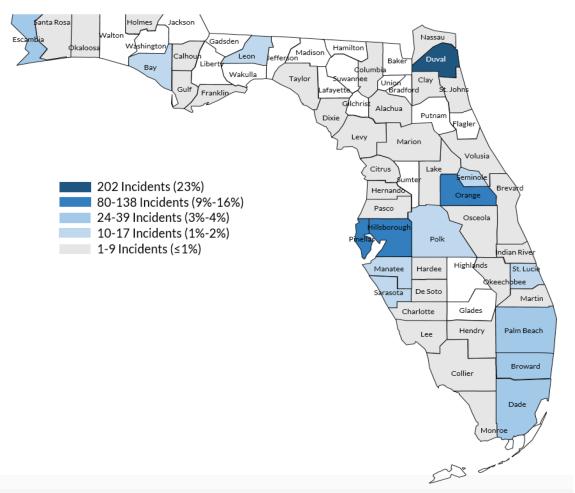


- MOST HAVE NOT BEEN UPDATED SINCE THE 1990s
- ► IGNORE ADVANCES IN TREATMENT AND PREVENTION
- DISPROPORTIONATE PUNISHMENT
- ► BURDEN OF PROOF LIES ON THE PERSON LIVING WITH HIV TO PROVE THEY DISCLOSED
- **▶ USED INCONSISTENLY**
- ► TARGET VUNERABLE POPULATIONS
- ▶ MOST DO NOT REQUIRE INTENT
- MOST DO NOT REQUIRE TRANSMISSION TO HAVE OCCURRED



EXAMPLE OF CRIMINALIZATION

Figure 2. Florida Counties Where HIV Criminal Laws Have Been Enforced







HIV Criminalization in the Media



- Media coverage of arrests and prosecutions of people living with HIV increase stigma and misinformation, especially when sensationalized or when the stories do not include accurate, relevant information about HIV and actual risks of transmission.
- These stories, along with criminalization itself, actually discourage testing ("take the test and risk arrest") and can make disclosure even harder than it already is, since it equates an HIV diagnosis with criminal sexual conduct and dishonesty in the minds of the public.
- Often, stories in the media bring up the HIV status of a perpetrator of actual sex crimes in ways that are sensationalized and not relevant to the story (e.g., when the person is not facing HIV-related charges and HIV was not transmitted, yet the person's HIV status is revealed in the article as a detail that makes the crime sound even worse). This reinforces stigmatizing ideas.



Reporting Responsibly About Criminal Charges Involving HIV



If you MUST report on criminal cases involving people living with HIV, here are some good guidelines to follow:

- Is the HIV status relevant to the story? If the charges do not include anything related to HIV, leave it out of the story.
- When the case involves charges of non-disclosure, avoid talking about "victims."
- Is it clear whether transmission occurred or has been proven? If not, include that caveat in the article. Transmission is generally not required for prosecutions, meaning people can be jailed for consensual sex where nobody contracted--or even could contract—HIV.
- ► Take the opportunity to include education about the current state of HIV prevention and treatment.



Reporting Responsibly About Criminal Charges Involving HIV



If you MUST report on criminal cases involving people living with HIV, here are some good guidelines to follow:

- Treat disclosure as the complicated matter that it is. Disclosing one's HIV status to partners and potential partners can be incredibly difficult, due to stigma and misinformation. If you know that you will not transmit HIV because of an undetectable viral load or because you always use condoms, disclosing to someone you do not plan on having a long-term relationship with may feel burdensome and unnecessary. In some cases, disclosure can lead to violence and coercion. Be sensitive to the challenges of disclosure and avoiding treating people as "victims" and "perpetrators" in cases involving consensual sex between adults.
- Avoid sensational headlines and ALWAYS use people-first language.

Learn more at pwn-usa.org/hiv-media-resources



Q & A

MORE INFORMATION

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