



UNDETECTABLE=UNTRANSMITTABLE:

Contextualizing a Campaign in the Lives of Women Living with and Vulnerable to HIV

WOMEN'S RESEARCH INITIATIVE ON HIV/AIDS (WRI)

HIGHLIGHTS

- **The Women's Research Initiative on HIV/AIDS (WRI), a program of The Well Project, is a multidisciplinary and multisectoral effort** dedicated to identifying gaps for women in HIV prevention, treatment and cure research and policy. In April 2018, The WRI convened a meeting to review the research and understand the science of the community-driven public health campaign Undetectable=Untransmittable (U=U) in order to contextualize it in the lives of women.
- **U=U means that when a person living with HIV is taking antiretroviral (ARVs) drugs** and their viral load has reached undetectable levels that are sustained over time, that person cannot sexually transmit HIV to a partner. Sexual transmission is one of a number of potential modes of HIV transmission relevant to women.
- **As the U=U message is being adopted by non-governmental and governmental agencies** around the world, the WRI sought to examine its relevance for women in the context of factors including: sexual relationships, motherhood, access to treatment, stigma and injection drug use.
- **The WRI 2018 validated the importance of U=U as a powerful approach**, both in terms of its public health message and as a tool to reduce HIV-related stigma, increase personal empowerment and improve health outcomes. The meeting also identified the limitations of extrapolating the compelling data supporting U=U for sexual transmission to other routes of transmission, such as breastfeeding and injection drug use.

BACKGROUND

U=U is a campaign that was launched by the Prevention Access Campaign in early 2016 in collaboration with people living with HIV. Together with global experts, they created a consensus statement on the science of U=U, which shows that when people

CONSIDERATIONS for U=U and WOMEN

- **Power dynamics, particularly within intimate relationships**
- **Access to HIV-related treatment and care**
- **HIV criminalization**
- **Pregnancy/breastfeeding**
- **Stigma**
- **Injection drug use**
- **Disclosure of HIV status**

living with HIV take ARVs daily and achieve and sustain an undetectable viral load they cannot sexually transmit HIV to their HIV-negative partners.

This consensus statement was based on extensive scientific research, including the following:

- **The “Swiss Statement:”** In the 2008 “Swiss Consensus Statement,” experts agreed the emerging data and lived experience among their clients demonstrated that a person living with HIV who had had an undetectable viral load for at least six months on ARVs and had no other sexually transmitted infection had a negligible risk of sexually transmitting HIV¹.
- **HPTN 052:** HPTN 052 was a large clinical trial that tested the concept of using ARVs to prevent sexual transmission of HIV. The study (whose final results were published in 2016) involved more than 1,700 mostly heterosexual, mixed HIV status couples in nine countries. No HIV transmissions occurred within couples in which the partner with HIV infection had a sustained undetectable viral load².

HIV to their partner is now supported by a wide range of organizations and agencies worldwide, including some, such as government entities, that cannot officially endorse or sign on to a campaign.

IMPACT OF U=U ON STIGMA

The WRI 2018 made clear that one of the greatest contributions of the U=U message for women (and men) is its potential to disrupt HIV-related stigma on both an individual and a population level.

By all accounts, stigma remains one of, if not the most significant barriers to ending the HIV epidemic. HIV-related stigma is defined as *prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV or AIDS and at the individuals, groups and communities with which they are associated*⁴. Stigma affects people on multiple levels, from internalization at the individual, psychological level to discrimination at the social-structural level.

Underpinning the U=U message is the idea that treatment as prevention and the science

“It’s really important to advocate U=U. People’s lives are on the line. U=U impacts criminalization and violence in relationships. People die because of fear of HIV. Women have been murdered after having their status found out.”

—Woman living with HIV panel participant, WRI 2018

- **PARTNER Study:** PARTNER was a prospective study of 1,166 heterosexual and gay, mixed HIV status couples in 14 European countries in which the partner living with HIV took ARVs and had an undetectable viral load. The 2016 results showed that after 58,000 instances of sex among couples who were not using condoms, there were zero cases of HIV acquisition within the couples³.

The science of treatment as prevention is compelling and clear. The message that a person living with HIV who has a sustained undetectable viral load cannot sexually transmit

of U=U can shift the narrative around people living with HIV and their bodies from one of “risk and stigma” to one of “safe and normal,” thereby reducing HIV-related stigma and all of its harmful consequences. Anecdotally, many people living with HIV report that the U=U campaign has dramatically increased their sense of hope and thus impacted their quality of life.

HIV criminalization is another important area of consideration for U=U. HIV criminalization refers to the use of criminal law to penalize alleged, perceived or potential HIV exposure. As of August 2017, 34 states, two territories



THE EFFECTS OF INDIVIDUAL, INTERPERSONAL AND STRUCTURAL HIV-RELATED STIGMA



- Avoidance of healthcare
- Negative emotions (e.g., silence, fear, shame)
- Fear of HIV disclosure/fewer disclosures
- Mental health pathologies
- Decreased HIV testing
- Death
- Loss of relationships/social isolation
- Discrimination (e.g., loss of employment, housing)
- Gender-based violence
- Decreased negotiation of safe sex practices
- Decreased access to services
- Criminalization

and the U.S. federal government had HIV-specific criminal laws⁵. These laws can be used to prosecute alleged nondisclosure of HIV-positive status prior to sexual contact [whether or not HIV is transmitted], as well as unintentional HIV transmission. Criminalization laws are known to be used disproportionately to prosecute women and people of color. In fighting to change these stigmatizing laws, the science behind U=U can help demonstrate why removing barriers to HIV care and treatment, including stigmatizing laws, is so important to the health and lives of people living with HIV. Legal teams may also use the science behind U=U for individual cases to prove no intended harm; however, U=U should not be used for broader HIV criminal law reform as it is vital that revised laws not stigmatize or criminalize people who, for whatever reason, may have detectable viral loads. For more information about criminalization, [click here](#).

U=U AND NON-SEXUAL TRANSMISSION FOR WOMEN

While the science of U=U for sexual transmission of HIV has been well studied and established, its application to other routes of HIV transmission relevant to women are less well-known. The WRI 2018 specifically discussed HIV transmission via breastfeeding and injection drug use.

Breastfeeding

Though there have not been studies specifically designed to determine whether a suppressed viral load eliminates the transmission of HIV via breast milk, a number of studies have data on this issue. These studies show that, while ARVs reduce the risk of HIV transmission through breastfeeding, it remains possible for women with an undetectable viral load to transmit

“U=U gave me a sense of hope. I’ve been living with HIV for 20 years and I haven’t been in a real relationship with anyone in a long time. But when I learned about U=U, it made me feel normal, it changed my life. And it’s changing other lives too. My community has a high prevalence of undiagnosed HIV. This is the thing that’s going to give women who look like me the empowerment they deserve.”

—Woman living with HIV panel participant, WRI 2018

HIV to their babies through this route. This is because breast milk contains many immune cells (the type of cells that HIV likes to infect), which are passed on to the baby during breastfeeding. While ARVs can reduce viral load, they cannot eliminate HIV from infected immune cells. In addition, overall breast health plays an important role in HIV transmission via breast milk because inflammation of the mammary gland increases HIV shedding in milk.

The WRI 2018 noted the importance of recognizing that women living with HIV consider a number of factors beyond scientific data when deciding whether or not to breastfeed their babies and providers must be willing to engage in honest dialogue with their patients about their decisions in order to best support them.

Injection Drug Use

WRI presentations and discussions revealed that while researchers are planning and currently undertaking studies to investigate whether suppressed viral load eliminates HIV transmission via shared injection equipment (needles and syringes), at this time there is insufficient data to extrapolate the U=U message to that mode of transmission for either women or men.

U=U AND RELATIONSHIP/POWER DYNAMICS

The underlying feature of U=U is durable viral suppression, which itself occurs in the broader context of women's lives. WRI participants identified relationship and power dynamics as key factors to consider when estimating the real impact of U=U on women. Some of the most important elements of these dynamics in relation to U=U are:

- Who makes the decisions about if, when and how to have sex

- Is there intimate partner violence in the relationship
- Trust/transparency between partners
- How partner relationships affect women's access to treatment and care
- Whether the woman feels sufficiently empowered in her relationship to ask for what she wants/needs
- Whether the partnership involves transactional sex (e.g., the exchange of sex for money, drugs or other material goods)
- Whether both partners in a relationship honestly disclose their HIV status

PERSPECTIVES ABOUT U=U AMONG WOMEN LIVING WITH HIV

Given the potential impact of U=U described above, it is vital to understand how that message has affected women living with HIV. At the WRI 2018, a panel of women living with HIV described how U=U has personally affected them, including eradicating internalized stigma, improving quality-of-life factors, increasing hope and generating the will to end the HIV epidemic. The panelists also addressed the urgency of U=U and its ability to effect change on a public health level. They described the importance of patient-provider dialogue in communicating U=U and the role of the biotechnology and pharmaceutical industries in supporting U=U messaging and efforts.

RESEARCH, POLICY AND ADVOCACY RECOMMENDATIONS

The WRI identified a number of research, policy and advocacy gaps that need to be addressed in order to optimize the impact of U=U among women.

- Develop and support a research agenda that seeks to address the following questions, among others:

“For me, this is about will. For the last several years, our scientific leaders have been saying that we now have the tools to end the epidemic, but do we have the will? U=U is a way to generate the will and inspire action.”

—Woman living with HIV panel participant, WRI 2018

- What impact does U=U have on the HIV care continuum for women?
- What, if any, quality-of-life outcomes can be attributed to the U=U message?
- Is U=U applicable to parenteral and perinatal transmission?
- What is the measurable impact of U=U on community and individual levels of stigma?
- What do different types of healthcare providers know and understand about U=U? What information gaps exist?
- Pursue policy efforts to include consistent U=U messaging in prevention, treatment and care guidelines in the United States and internationally.
- Incorporate consistent U=U messaging in training and education programming, including in sex education instruction, medical school curriculum and CME requirements.
- Engage in advocacy efforts that leverage

the U=U message to mitigate stigma, discrimination and criminalization.

- Leverage existing/ongoing local, national and international “campaigns to end AIDS” to include messaging about and examples of successful programming around U=U.
- Undertake a broad-scale public health campaign to educate the general public about U=U with the goal of shifting the population’s thinking about HIV/AIDS.
 - Engage thought-leaders and celebrities in this effort to optimize the campaign’s reach.

CONCLUSION

U=U is an important tool with the potential to significantly alter the trajectory of the HIV epidemic by changing the way people living with and vulnerable to HIV see themselves and are seen by others. To realize its potential among women, the message must be clear, consistent, evidence-based and relevant to all women.

REFERENCES

1. Vernazza P *Presentation in HIV Transmission under ART*. Symposium session SuSat41, seventeenth International AIDS Conference, Mexico City, 2008
2. <https://www.nejm.org/doi/full/10.1056/NEJMoa1600693>
3. <https://jamanetwork.com/journals/jama/fullarticle/2533066>
4. <http://journals.sagepub.com/doi/pdf/10.1177/0002764299042007004>
5. <https://www.hivlawandpolicy.org/resources/chart-state-state-criminal-laws-used-prosecute-people-hiv-center-hiv-law-and-policy-2012>.

ABOUT THE WRI

*Since 2003, the Women’s Research Initiative on HIV/AIDS (WRI), a program of The Well Project, has advocated for “more, better and faster research” in HIV disease in women. The WRI brings together an extraordinary group of leaders in HIV to identify key opportunities to accelerate our understanding of HIV disease in women. WRI members represent a broad range of stakeholders in the fields of clinical care, research, academia, community-based services, advocacy, government, the pharmaceutical industry and women living with HIV. This diverse membership operationalizes the multidisciplinary approach advocated by the WRI. By addressing issues that affect women through a variety of lenses, the WRI is able to expand understanding of effective treatment and prevention for women and girls living with or vulnerable to HIV. Please **click here** for more information on the WRI.*

ABOUT THE WELL PROJECT

*The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. The Well Project is the premier online resource on women and HIV both nationally and globally, revolutionizing the availability and accessibility of meaningful and relevant information designed specifically for women and girls living with HIV. Focusing on three critical areas related to women and HIV—information access, community support, and advocacy—The Well Project is leveraging technology to dramatically improve health outcomes and quality of life for women and girls living with HIV. Please **click here** for more information on The Well Project.*

