# Living in the Asterisk (\*)

What does U=U mean for women?

2024 Women & HIV/AIDS

#### Acknowledgements

The development and updating of this resource connects to our gratitude to the land we live on, the communities where we work, our commitment to working against deep systems of racism and colonialism, and toward equity. WHAI acknowledges that our work happens on the various unceded, occupied lands traditionally belonging to the many First Peoples across Ontario, including the ancestral and current lands of a diverse range of First Nations, Métis and Inuit peoples. We honour the many treaties, views and practices of First Peoples living on this land now and throughout history. We ground our ongoing work in listening, reflection and actions of solidarity in support of movements of justice and

self-determination for First Nations, Métis and Inuit peoples in Ontario. We bridge our settler and immigrant experiences and histories on the land with feminist transnational movements seeking freedom from settler occupation and colonialism.

We acknowledge the leadership of the communities we work with across Ontario in leading this work and its deep alignment with racial, gender and health equity. In particular, we are grateful for input, leadership, and critical analysis from Alex Mlynek, Amanda Leo, HALCO, HIV Legal Network, Loop:Design for Social Good and Dr. Malika Sharma.

Women (\*) Throughout this document the term "women" is written in colour to remind us of the importance of prioritizing and centring communities of women who face disproportionate structural risk factors related to HIV. To read more, see the "Welcome" section on the following page.

#### Welcome

This resource was developed by the Women & HIV / AIDS Initiative (WHAI) in 2017 and updated in 2024 to support our community development work. Through a network of 17 Coordinators located across Ontario, WHAI aims to:





Reduce HIV risk for women disproportionately affected by HIV

Enhance local community capacity to address HIV

Build safer environments to support women's HIV-related needs.

WHAI seeks to be informed by and amplify the experiences of those who face structural discrimination and exclusion, which impacts HIV risk and the health outcomes of those living with HIV. As such, our work focuses on engagement with cis and Trans **women**, 2-Spirit and Non-Binary people who are living with HIV, who are African, Caribbean, Black, Indigenous or newcomers, who use drugs or substances, have experiences with violence and / or have been / are incarcerated.

This document seeks to reflect the voices, concerns and lived realities of these populations in relation to Undetectable=Untransmittable (U=U) messaging. This resource is intended to be used to support community conversations about HIV and the U=U messaging within the communities where we work.

The current version of this resource has been updated to reflect changes in language, science and the current landscape of HIV care and prevention in Ontario, as well as identify and address questions and gaps that continue to be important in our work. In WHAI's Collective Action Community Change consultation process, **188 participants were asked about their familiarity with the concept of U=U** or Undetectable=Untransmittable. **54% answered "No, they were not familiar with U=U."** Read more at <u>whai.ca/</u> <u>resource/by-the-numbers-</u> <u>what-weve-learned</u>

To read more about WHAI's work across Ontario and our principles of community development and collective impact, visit whai.ca/work

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#### Undetectable=Untransmittable

Undetectable=Untransmittable (U=U) is a campaign that began in mid-2016, led by the Prevention Access Campaign (PAC). The PAC consensus statement is based on rigorous research showing that when a person living with HIV takes HIV treatment medications and maintains an undetectable viral load for at least six months, the risk of transmitting the virus through sex is negligible, or essentially zero. The messaging of the consensus statement is clear, definitive, prioritizes the importance of keeping people engaged in care, empowers people living with HIV to have full and healthy sex lives, and is a powerful and important tool in challenging stigmatizing perceptions about people living with HIV. This research has included women and women's experiences, and is an important step forward in the prevention of HIV through sexual transmission and the rights of people living with HIV.

While this research is transformative, we have added an asterisk (\*) to the U=U campaign that represents important considerations and intersectional<sup>+</sup> realities, many of which are particularly relevant for WHAI's priority populations. The U=U campaign is not messaged with this asterisk, but the realities of this asterisk represent many people's lives, and the importance of centring these experiences in our efforts against HIV.

Read the full updated PAC consensus statement at preventionaccess.org/wp-content/uploads/ 2021/07/UU-Consensus-Statement.pdf



#### AT A GLANCE:

When a person living with HIV takes HIV treatment medications and maintains an **undetectable viral load for at least six months**, the risk of transmitting the virus through sex is negligible, or essentially zero.

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"intersectionality" was coined by Kimberlé Crenshaw to describe how structural factors connect and impact people's health outcomes. This includes factors such as racism, misogyny, classism, transphobia and more.<sup>1</sup>

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Teresa Group offers formula in Ontario free of charge! <u>teresagroup.ca/index.</u> <u>php/what-we-do/infant-</u> <u>formula-program/</u>

#### Does U=U Apply to Breastfeeding/Chestfeeding?

#### SHORT ANSWER:

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**Sometimes it does, and sometimes it doesn't**. It's important to understand which factors might apply to you.

For parents, issues related to breastfeeding/chestfeeding while living with HIV can be difficult. Some key considerations include:

- New recommendations exist to support breastfeeding/chestfeeding in certain circumstances, including recommendations for frequent parental viral load monitoring to stay undetectable, regular follow up of both parent and baby, and treatment and monitoring of baby with medications that treat HIV. This should be an informed discussion between parents and their healthcare providers, with the opportunity to ask questions and understand risks and benefits of each individual's circumstances.<sup>2</sup>
- HIV treatment taken by people living with HIV and their babies during breastfeeding/chestfeeding can dramatically lower the risk of transmission through breastmilk, but the risk is still not zero<sup>2</sup>

- HIV can be present in breast/chest milk even when undetectable in the blood, especially when the breast tissue is inflamed (e.g., with engorgement or mastitis)<sup>2</sup>
- U=U has been studied in relation to sexual transmission, but this research cannot be applied directly to breastfeeding/chestfeeding
- Canadian guidelines recommend exclusive formula feeding for all babies born to birthing parents living with HIV. Formula is available across Ontario through the <u>Teresa Group</u> free of charge.

Find more information about HIV and breastfeeding/chestfeeding through the following links:



- jammi.utpjournals.press/doi/ pdf/10.3138/jammi-2022-11-03
- <u>catie.ca/the-power-of-undetectable-</u> <u>what-you-need-to-know-about-hiv-</u> <u>treatment-as-prevention/having-an-hiv</u>
- <u>catie.ca/catie-statement-on-the-use-of-</u> <u>antiretroviral-treatment-art-to-maintain-</u> <u>an-undetectable-viral-load</u>
- <u>ohtn.on.ca/hiv-transmission-through-</u> <u>breastfeeding/</u>
- <u>chiva.org.uk/should-mothers-living-</u> <u>with-hiv-breastfeed-their-babies/</u>



#### Does U=U Apply to People Who Use Drugs?

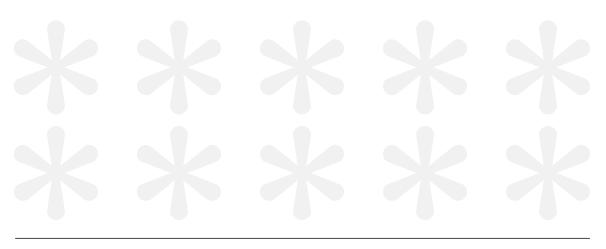
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#### SHORT ANSWER:

Unfortunately, there is not adequate research about U=U and transmission through drug use equipment; however, being on treatment and maintaining an undetectable viral load prevents transmission through sex for everyone, including people who use drugs.

- Currently and historically, women who use injection drugs represent a significant proportion of those who acquire HIV<sup>3</sup>
- Gender impacts patterns of drug use and needle-sharing, which can contribute to risk of HIV acquisition<sup>4</sup>

- Research has shown that, for many different reasons, people who use drugs are less likely to reach and maintain an undetectable viral load<sup>5,6</sup>
- We do not have adequate research about U=U and transmission through shared drug use equipment; however, we know that being on treatment and maintaining an undetectable viral load prevents transmission through sex for everyone, including people who use drugs<sup>7</sup>
- As a result, the U=U messaging cannot be applied to transmission risk through drug use, which is particularly relevant to women who use drugs



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#### Achieving Undetectable Viral Loads

- Social<sup>8</sup> and structural<sup>9</sup> determinants of health significantly impact who is at risk of acquiring HIV, who has access to prevention strategies and treatment, and who is able to achieve successful treatment outcomes<sup>10</sup>
- Canadian research that studied a mixed gender group on HIV treatment showed that women are significantly less likely to achieve <u>viral suppression</u> and therefore are less likely to be undetectable, are at increased risk for viral load rebound and, in turn, have poorer health outcomes<sup>11</sup>
- Women are less likely to achieve undetectable viral loads for various reasons including being diagnosed later in life, prioritizing the health of others, higher rates of poverty, violence, housing instability, food insecurity, immigration status, racism and more.<sup>12</sup> These realities can be extended and amplified for Trans, 2-Spirit and Non-Binary people.<sup>13</sup>
- U=U messaging may be less achievable for women because of these structural realities

Read the WHO's guidance on HIV viral suppression at who.int/news/item/23-07-2023-new-who-guidanceon-hiv-viral-suppression-and-scientific-updatesreleased-at-ias-2023

#### AT A GLANCE:

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Undetectable viral loads may be less achievable for those who face social and structural inequities.

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### A Hierarchy of (Un)detectability

- There are many reasons why some people may be unable to achieve an undetectable viral load. For example, not everyone has access to testing, care and treatment, some people face barriers to accessing medication, and others continue to have detectable viral loads even with treatment.
- U=U messaging has the potential to create a hierarchy among people who have achieved an undetectable viral load and those who have not, resulting in those who are detectable being further stigmatized. This hierarchy is also reflected in the risk for criminalization for individuals who do not have an undetectable viral load.
- As this resource shows, women are less likely to be virally suppressed, and therefore this potential hierarchy has particular implications for women
- U=U=U: There has been a more recent push to include a third "U" for "universal" to foster dialogue and efforts to eliminate the hierarchy of undetectability given the lack of equity in access to HIV treatment and thoughtful, inclusive care<sup>14</sup>

AT A GLANCE: It is important to be aware of the hierarchy that the idea of "undetectability" can create within an already stigmatized community.

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#### U=U and HIV Criminalization

As the U=U campaign has gained popularity, it has been used in advocacy efforts to help change laws that criminalize people living with HIV. Most of the people charged with a criminal offence relating to HIV have been charged with aggravated sexual assault for not disclosing their HIV positive status before having sex. While the law has changed over the years, it is still being used against people living with HIV. Currently, certain scenarios require HIV disclosure while others do not.

U=U suggests that risk is basically zero if someone has a suppressed viral load, even if no condom is used. The discrepancy between this principle and the practical application of the law in both Ontario and across Canada can lead to confusion in decision-making about disclosure obligations:

- One example of how the law is disproportionately used against women is ongoing fear about criminalization related to pregnancy and breastfeeding. In part, this relates back to one case in Ontario (2005) where a woman living with HIV was convicted in relation to breastfeeding. In this case, the woman also did not take treatment during pregnancy to prevent HIV transmission to her infant, and did not inform medical staff of her HIV status when she gave birth, contributing to the charges.<sup>15</sup> These types of experiences of criminalization contribute to fear amongst others in the community (see page 5 for more information).
- Laws are inconsistently applied across the country and often demonstrate a racial bias

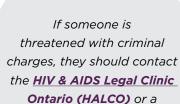
- "A gendered analysis of the current use of the criminal law with respect to HIV reveals that criminalization is a blunt, punitive and inflexible approach to HIV prevention that does little to protect women from HIV infection, violence, coercion or sexual objectification."<sup>16</sup>
- U=U messaging should NOT suggest that people living with HIV and who have a detectable viral load may be deserving of criminalization

For guidance about the law and when it is required to disclose HIV status and when it isn't, visit <u>halco.org/</u> wp-content/uploads/2023/10/HIV-andthe-Criminal-Law-in-Ontario\_Update September-2023-002.pdf

AT A GLANCE:

The law has changed over time, but it is still being used against people living with HIV and demonstrates inequities in how it is applied, often based on race and gender.

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criminal lawyer.

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#### What's Next?

### The U=U campaign has been transformative for many people living with HIV.

The U=U discussion requires space for open and engaging conversations about marginalization, discrimination and structural barriers to health and **women**'s experiences of these structural barriers. This is an important part of WHAI's community development work in Ontario. The issues raised in this document reflect complexities that have emerged in our conversations across Ontario. **Women**'s voices, and the nuances included in the asterisk are important to centre in our community conversations about U=U.

In our communities across Ontario, we are working to celebrate the advances in science, while centring the lived realities represented by the asterisk, and working toward collectively addressing stigma against all people living with HIV.

> "U=U completely changed how I think about HIV and wellness. Wish it was more widely taught in high school and universities, [they] still have incorrect opinions about HIV. Campaigns like U=U are very important in education people."

- Community voice from Ottawa

Quotation taken from WHAI's Collective Action Community Change consultation process done in 2021 / 2022. To read more, see <u>whai.ca/resource/</u> <u>collective-action-community-change-a-</u> <u>report-amplifying-community-voices/</u> "There is a general lack of knowledge about U=U even among women who are living with HIV."

- Community voice from York Region

#### References

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