Undetectable=Untransmittable

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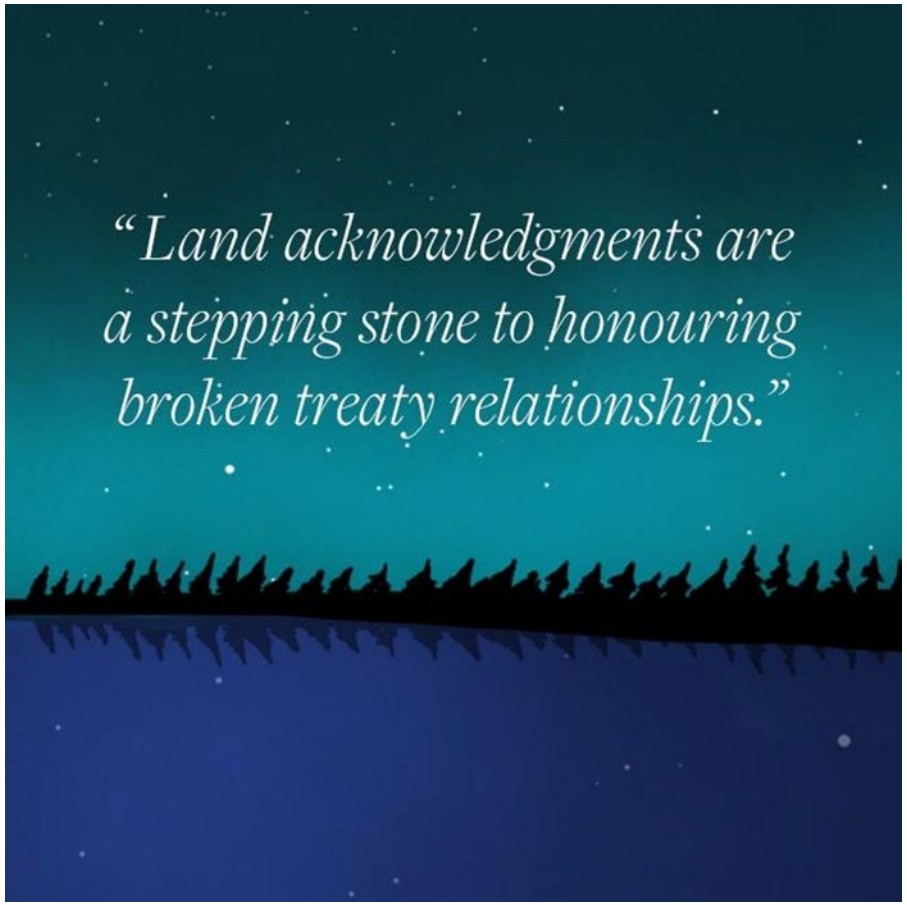
Land Acknowledgement



WILLIAMS TREATIES FIRST NATIONS

Agenda

- 1. Introductions
- 2. Webinar outline and procedure
- 3. U=U: Definition and research
- 4. Alberta Stigma Index, demographics, U=U quantitative and qualitative data
- 5. U=U & pregnancy and breast/chest feeding
- 6. Language
- 7. The Third U: Universal; Unequal
- 8. Film: HIV made me Fabulous
- 9. What now?
- 10. Resources
- 11. Acknowledgements
- 12. Discussion

Definition of U=U

- If someone is HIV Positive, on treatment and maintains an undetectable viral load, they cannot transmit HIV sexually to their partner
- In the studies conducted, an undetectable viral load is achieved when someone has a viral load under 200 copies per ml. of blood
- **When HIV is undetectable, it is untransmittable**

Research Behind U=U

Treatment as Prevention

In 1996, Dr. Julio Montaner at the BC Centre for Excellence in HIV/AIDS, reported on HAART (Highly Active Antiretroviral Treatment) at the International AIDS Society conference in Vancouver. He built on that research and began to talk about Treatment as Prevention in the late 90's. He found that his patients who were virally suppressed were not transmitting HIV to their seronegative partners.

The "Swiss Statement"

In the 2008 "Swiss Consensus Statement," these experts agreed, based on new data and what they were documenting among their patients, that an HIV-positive person who had an undetectable viral load for at least six months and continued to take HIV treatments had a negligible risk of transmitting HIV (risk is so small or unimportant that it is not worth considering).

(Sources: preventionaccess.org, catie.ca)

Research Behind U=U

HPTN 052

HPTN 052, published in 2011, was a large study involving more than 1,000 mostly heterosexual, mixed-status couples, where one person was on anti-retroviral treatment and undetectable and the other was HIV negative.

PARTNER 1 and 2

- The PARTNER 1 study (2014) looked at the risk of HIV transmission in heterosexual and gay mixed-status couples in which the partner living with HIV took HIV treatment and had an undetectable viral load.
- The study results in 2016 showed that after 58,000 instances of sex among 1,166 couples who were not using condoms, there were zero cases of HIV acquisition within the couples: none from anal or vaginal sex; or to women; or to people living with other sexually transmitted infections (STIs).
- Findings from PARTNER 2 (2018), the second phase of the PARTNER study, provided conclusive evidence that U=U is as applicable to gay, bisexual, and other me who have sex with men as it is to male-female couples.

Sources: preventionaccess.org, catie.ca

Alberta Stigma Index

From 2019 to 2021, peer researchers with the Alberta Stigma Index carried out a quantitative and qualitative study looking at the experience of stigma in people living with HIV in Alberta.

Demographic Summary of Survey Respondents

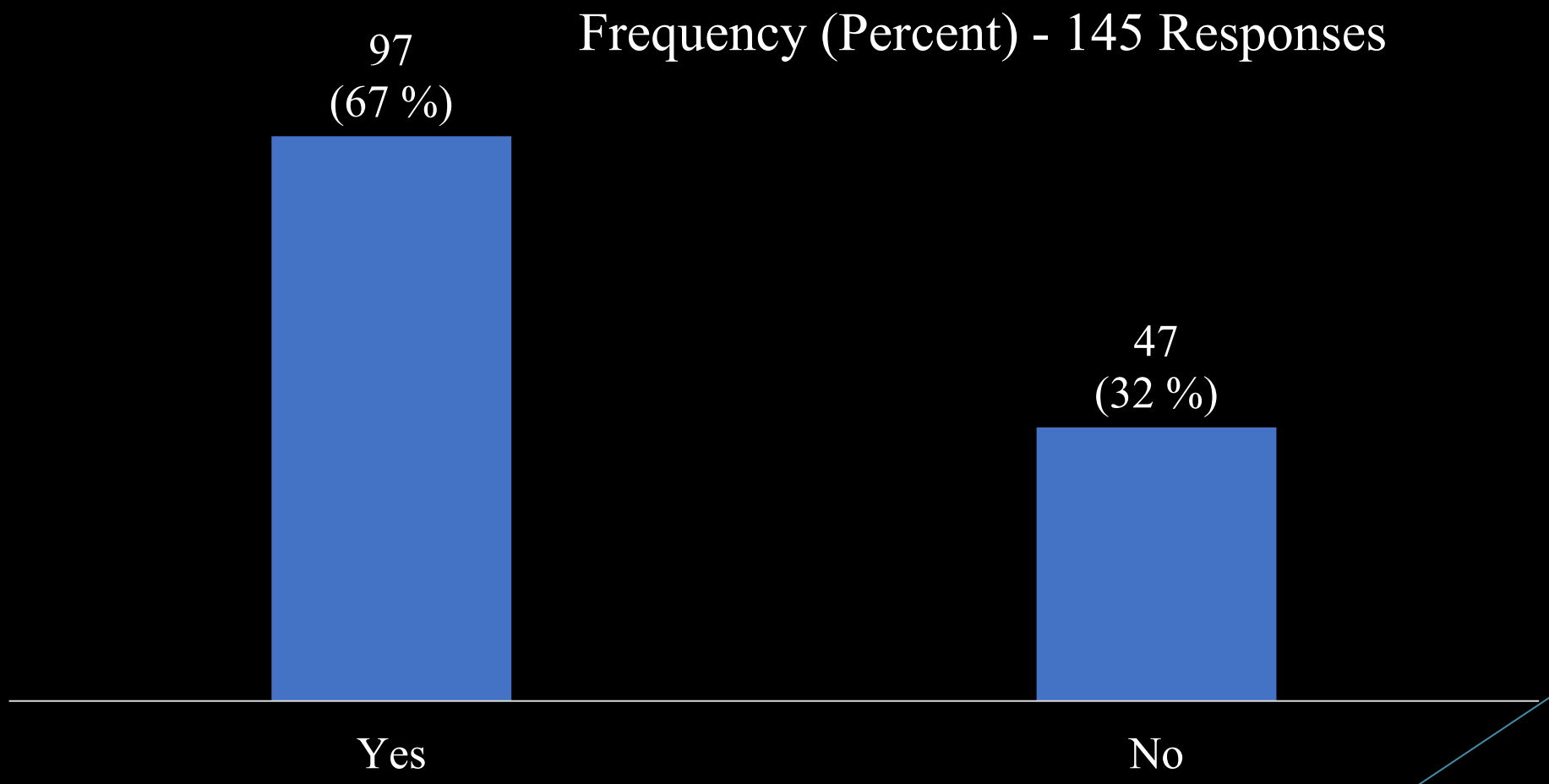
Category	Sample	
Gender	63 % Male	34 % Female
Sexuality	58 % Heterosexual	30 % Gay
Ethnic and Racial Identity	54 % Caucasian 29 % Indigenous 18 % African, Caribbean, Black	
Rural/ Urban	97 % Living in a large town or city	
Employment Status	39 % Receive Disability	23 % Unemployed
Relationship Status	65 % Single	25 % In a Relationship or Married
Education	52% Have completed high school as their highest level of education	

Stigma and Discrimination Overview

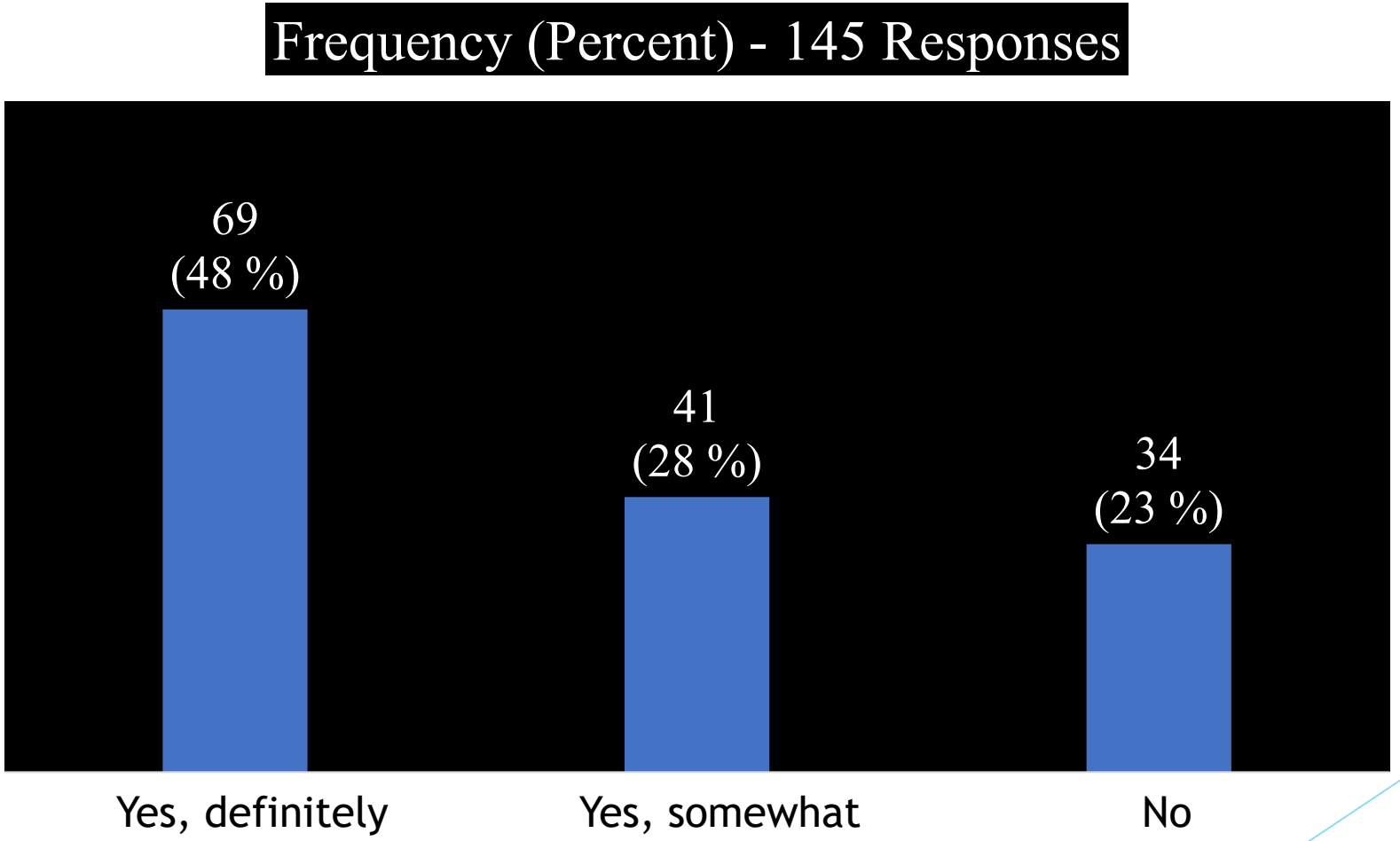
Respondents to the Alberta Stigma Index reported:

- That they have decided to not have sex or sexual relationships in the past 12 months because of their HIV status.
- Their HIV status negatively impacted their ability or willingness to have close and secure relationships with others.
- That they anticipated that romantic or sexual partners would treat them differently.

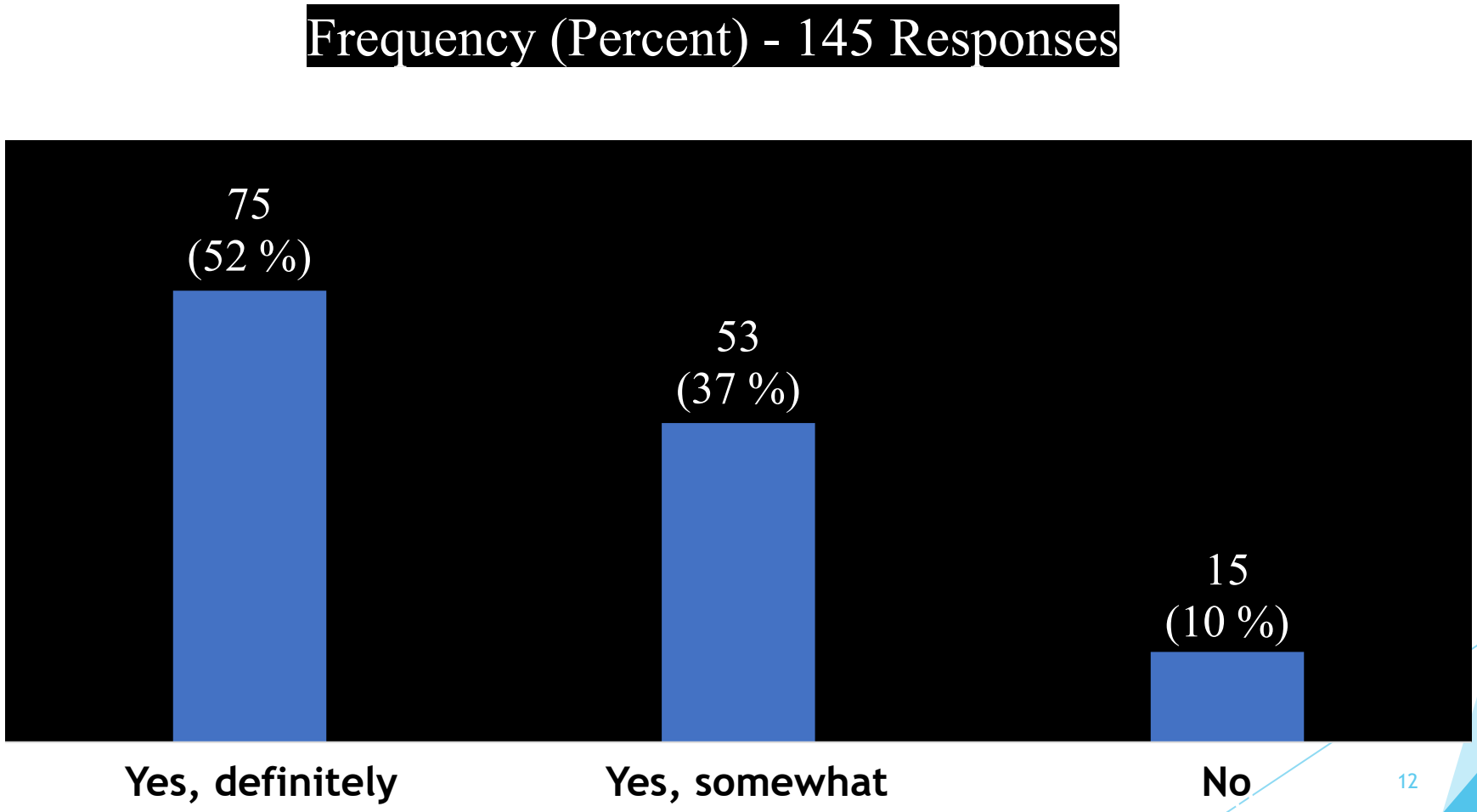
Have you heard about the U=U message?



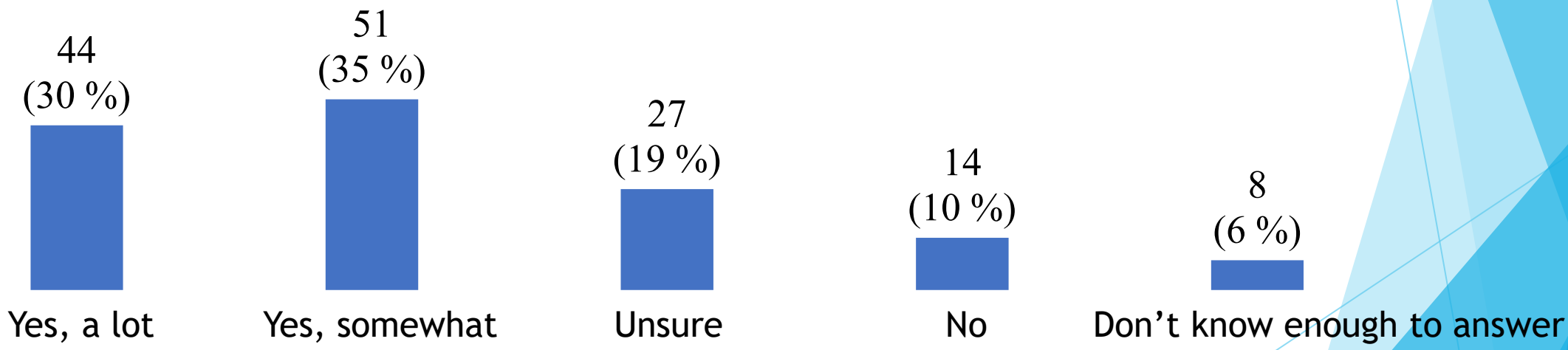
Are you aware of the scientific evidence supporting U=U that sexual transmission is not possible if a person living with HIV is on antiretroviral medications for at least 6 months and is undetectable?



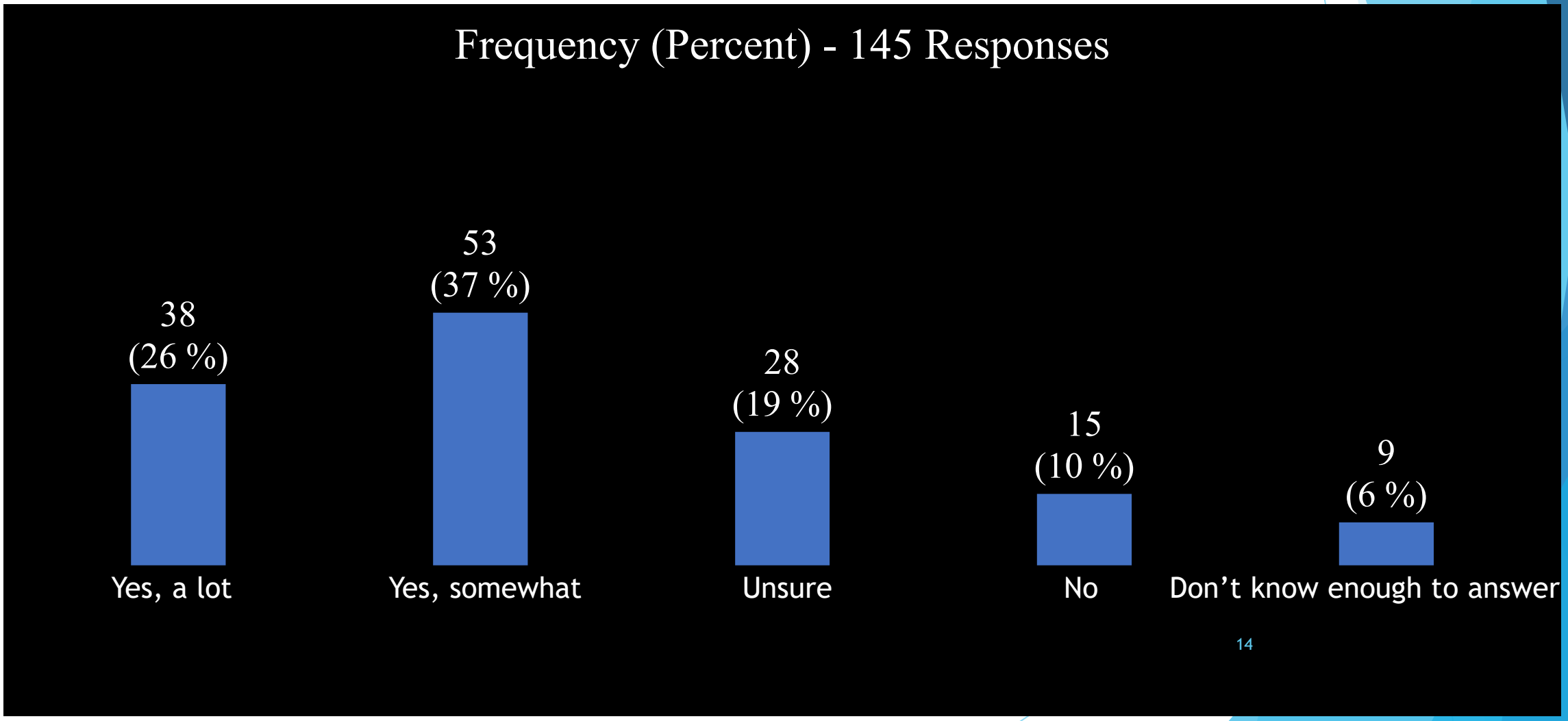
Do you accept / believe the U=U statement that sexual transmission is not possible if the person living with HIV is on antiretroviral medications for at least 6 months and is undetectable ?



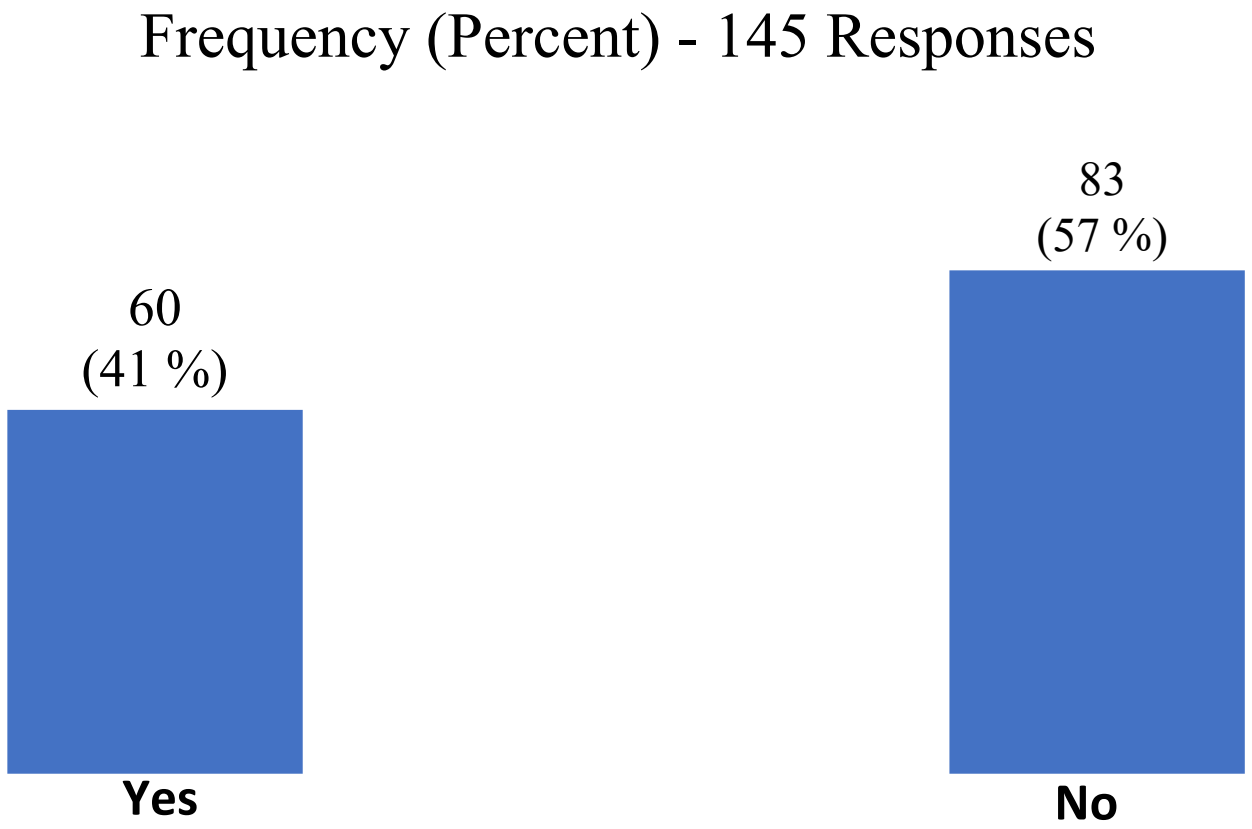
Do you think that the people who are the most judgmental in regard to your / others' HIV positive status would change opinions about people living with HIV if they were educated / aware of the U=U statement / message?



Do you think the promotion of the U=U statement / message will reduce HIV stigma?



Has your primary HIV healthcare provider discussed the U=U message with you?



Alberta Stigma Index Qualitative Interviews: U=U

- Qualitative interviews conducted with people living with HIV in Alberta have highlighted the importance of the U=U message in combatting the stigma associated with HIV.
- It is emerging from the interview analysis that the U=U message has an impact on reducing the public fear associated with HIV infection, improving the quality of life for those living with HV, and can be an important tool in the fight against stigma

"I think educating people on U=U and things like that, and the science behind that, is absolutely integral to dealing with stigma".
(person living with HIV in Alberta)

Alberta Stigma Index Qualitative Interviews: U=U

"It wasn't until about a year and a half ago that my doctor actually told me I couldn't transmit HIV with an undetectable viral count. And the reason they didn't tell me - I asked them about this - he goes, "Well if told you, you would probably have syphilis." I had no idea! And for years - years - that was never given to me, as honest as I was with my medical professional, he was not honest with me. He did not give me good news, he kept me on the edge of the ledge … I take offense at that."

"In some aspects it(stigma) has got so much better because the science behind U=U. Things like that has really removed a lot of stigma and a lot of that fear that people have. That has really had a huge impact on people's lives."

(quotes from people living with HIV in Alberta).

HIV & infant feeding Guidelines &U=U Advocacy

knowledge for self advocacy

Breast/Chest Feeding – The Current Global Context

- In 2016, the World Health Organization (WHO) acknowledged the accumulating evidence showing that giving antiretroviral medicines to the person living with HIV or the infant can significantly reduce the risk of transmission through breast/chestfeeding. For the first time, WHO recommended that HIV-positive parents or their infants take antiretroviral drugs throughout the period of breastfeeding and until the infant is 12 months old.

- In developing nations, the recommendation is generally that parents living with HIV should breast/chest feed for at least 12 months and may continue breast/chest feeding for up to 24 months or longer (similar to the general population) while being fully supported for ART adherence.

- In developed nations the recommendation is generally that parents living with HIV should not breast/chest feed rather formula feed baby.

Breast/Chest Feeding – The Current Canadian Context

- In Canada, it is currently recommended that people living with HIV avoid breast/chest feeding and use formula in order to prevent HIV transmission, which is possible through the consumption of breast/chest milk.

- WHO recommended that national health authorities from each country refer to this evidence when formulating their strategy on infant feeding. Health Canada however has not yet issued new guidelines in response to the updated WHO recommendations.

- The elimination of any risk of HIV transmission is often the only factor considered in counseling parents about infant-feeding decisions. This ignores challenges related to health disparities and family, cultural, and economic values, as well as the potential benefits and advantages of breast/chest feeding..

Expert Consensus Statement on Breastfeeding and HIV in the United States and Canada (2020)

- In October 2020, a multi-disciplinary, multi-sectoral group of 23 experts from the United States and Canada convened to identify and discuss the top priorities to ensure that parents living with HIV are able to make the best infant-feeding decisions for themselves and their babies.

- The statement acknowledged that breast/chest feeding is the standard of care in low-resource settings where it has been consistently demonstrated to promote the overall survival and well-being of HIV-exposed infants, with an extremely low risk of HIV transmission when the breast/chest feeding parent has sustained viral suppression.

- Insistence on a “zero-transmission-risk” choice concerning breast/chest feeding is at odds with the autonomy of parents living with HIV and their fundamental right to make informed choices about their children’s care without judgment or interference from providers or government

Consensus Statement Calls to Action

- **Recognize, account for, and advocate to change the intersectional conditions** that specifically impact women living with HIV, particularly as they relate to their infant-feeding decisions

- **Understand and respect the fundamental right** of women and other birthing parents to make informed, uncoerced choices about their sexual and reproductive health, contraception, pregnancy, and medical care, and about the care of their children.

- **Develop provider education and tools** to address the complex realities facing parents living with HIV in their infant-feeding decisions and their rights to make informed decisions about the best course of care and treatment for their children

Consensus Statement Calls to Action

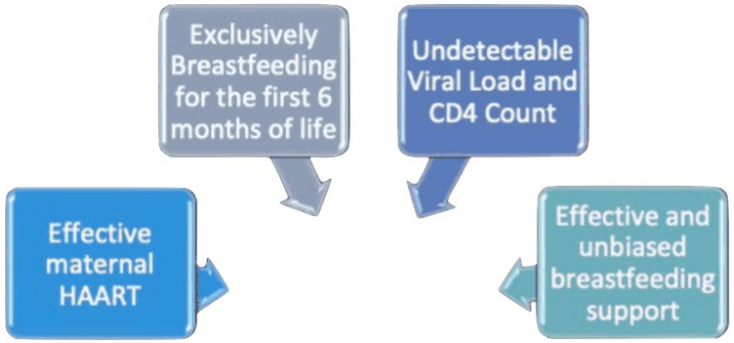
- **Create parent resources and support peer-to-peer systems** to provide parents living with HIV with comprehensive education and support around infant feeding\
- **Engage in policy reform** to ensure guidelines reflect the rights of women and other birthing parents to parent their children and best practices; center their intersectional lived experiences and agency; and address the criminalization of women living with HIV, including those who breastfeed
- **Advance research** to understand existing data on HIV and infant feeding and identify and address remaining knowledge gaps

What we know so far ……

- There is mounting evidence that the rate of transmission of HIV through breast/chest feeding for women who are on ART and have a stable undetectable viral load are extremely low and, in some studies, as low as less then 1%.

- We know Antiretroviral treatment effectively reduces viral load (and mother-to-child transmission), but for a variety of reasons many women do not effectively achieve and maintain undetectable viral loads throughout pregnancy and breastfeeding. Current approaches to viral load monitoring are poorly implemented and the response to high viral load measurements is suboptimal; thus the risk of breast milk transmission by women taking antiretroviral drugs has not been entirely eliminated.
- We also know that Insistence on a “zero-transmission-risk” choice concerning breast/chest feeding is at odds with the autonomy of parents living with HIV and their fundamental right to make informed choices about their children’s care without judgment or interference from providers or government

British HIV Association Guidelines(BHIVA)



In 2018 these guidelines were updated to acknowledge that the risks of transmission associated with WLWHIV may be exaggerated in an era of effective antiretroviral treatment

The guidelines recognize that some mothers living with HIV may want to breast-feed and if they do then detailed recommendations are offered to support them.

You Have Choices
You Have Rights

- Current guidelines are outdated and are not based on current U=U science
- You have the right to make choices about your reproductive health and infant feeding goals
- A person centered approach is needed from clinicians and service providers that includes the informed decision to breast feed
- Women living with HIV who wish to breastfeed should be respected for their decision and given proper medical guidance and resources
- WLWHIV who decide to breastfeed should not have to be in fear of legal and child protection services involvement.

Self-Advocacy Tips and Things to Keep in Mind

- Talk to your specialist or doctor about your reproductive and infant feeding goals
- Create a plan of care with your doctor that works for you
- You have the right to make your own decisions about infant feeding
- WLWHIV have successfully breastfed their infants with zero HIV transmission
- U=U!!!!!!

The Third U= Universal; Inequality

"…some people in Canada living with HIV do not have equitable access to ART (anti-retroviral therapy)….Our collective celebration of U=U is undermined if access to testing, treatment, care, and support — and viral suppression — is not universal. We need to think critically about the ways colonialism, race, class, gender, gender identity, sexual orientation, immigration status, incarceration history, and other factors may affect access to healthcare and experiences of stigma. Access to HIV treatment and its desired outcome — an undetectable viral load — is a right, and lack of access to treatment is a violation of that right."

https://www.catie.ca/uu-a-guide-for-service-providers/the-third-uuniversal-viral-load-does-not-equal-value-vv

The Third U= Universal; Inequality

A study carried out in Southern Alberta and published this year by CATIE, found that people living with HIV who live in rural areas had "delayed access to HIV-related care and delays in initiating antiretroviral therapy after an HIV diagnosis (and that)...Once non-urban people were in care, they were slightly less likely to remain in contact with the clinic and were more likely to have unsuppressed HIV up to three years after an HIV diagnosis."

catie.ca/comparing-health-outcomes-among-people-with-hiv-in-urban-and-non-urban-alberta

Film: HIV made me Fabulous

“HIV Made Me Fabulous” is a film that tells the personal story of Juno Roche, a writer, activist, and trans woman, who has been living with HIV for over 25 years. Grounded in HIV science, the film examines issues related to HIV, intersectionality, and health equity.

Acknowledgement: Kilpatrick, E. (Film Producer and Director), Roche, J. (Writer and Narrator), Carter, A. (Co-producer), & Kaida, A. (Co-producer). (2021). HIV Made Me Fabulous. Simon Fraser University; lifeandlovewithhiv.ca

Language is important when talking about U=U

Say:

- Can’t Pass it on
- Can’t Transmit
- No risk
- Zero risk
- Prevents HIV
- Eliminates onward transmission

Don’t Say:

- Negligible
- Greatly Reduces
- Extremely unlikely
- Virtually impossible
- Close to zero
- Helps prevent
- Makes it hard to

(Sources: preventionaccess.org, catie.ca)

What do we do now?

From 2020 to 2021, peer researchers with the Alberta Stigma Index carried out 5 webinars to the public and healthcare professionals on the subject of U=U. The sessions with healthcare professionals (primarily nurses who provide care to people living with HIV) were intended to change their practice to providing information on U=U to the people living with HIV whom they support.

“Healthcare professionals need to inform patients living with and affected by HIV about U=U to improve, first and foremost, personal health, as well as public health; sharing this information might greatly improve the social and emotional wellbeing of people living with HIV, reduce HIV stigma, reduce anxiety associated with HIV testing and help motivate treatment uptake, treatment adherence and engagement in care.”

(Beyrer C, Richmond B, et al. (2021) Call to action: How can the US Ending the HIV Epidemic initiative succeed? Lancet.; Cited by preventionaccess.org)

“There is great new work before us, which is to replace with true knowledge the ignorance that has destroyed human minds. We will construct unity in a world which has been brutally torn apart by false divisions of race, religion, gender, nationality, and age.

We will heal with unconditional love those souls whose hearts have been disfigured by hatred and loneliness.”

Aberjhani, Songs from the Black Skylark

U=U Resources

For more information on U=U, visit catie.ca or preventionaccess.org

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