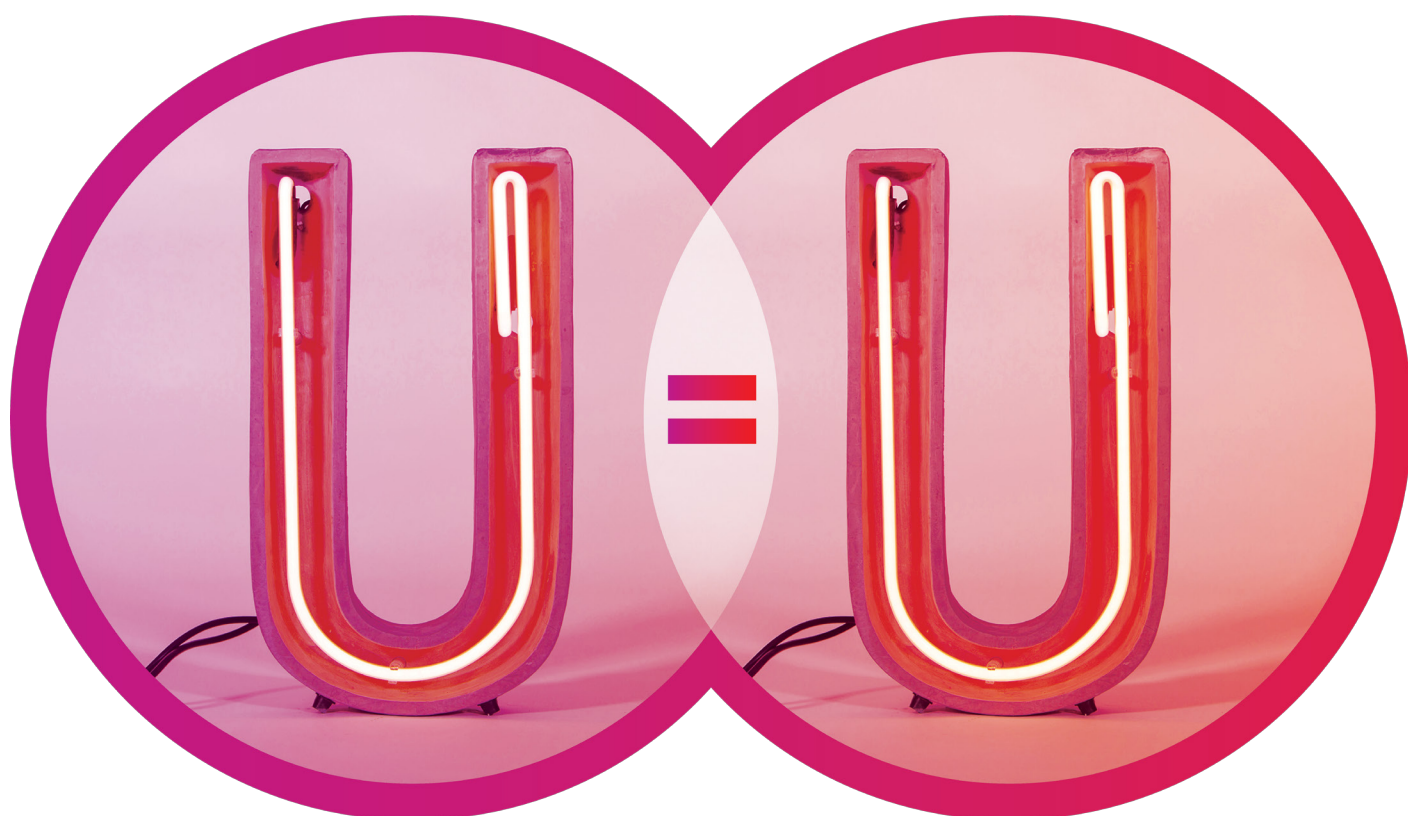


Understanding U=U for women living with HIV

ICASO Community Brief

September 2018



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Foreword for the U=U ICASO resource

September 2018

Dear Reader

The U=U movement is transformative . . . so profound in its implication and impact but so simple in its concept. And women - all women everywhere - too must benefit from this concept.

Concepts only bring benefits when they are embraced and implemented.

I am hopeful that U=U will in the next few years pervade every area of women's' lives, every care givers' attitudes and practice and every policy makers' decisions.

We have known for some time now that women who are on antiretroviral therapy and have undetectable viral loads can, if they wish, safely conceive, carry to term, deliver and breastfeed their babies free of anxiety.

Similarly, if they or their intimate partner have undetectable viral loads then sexual intimacy can be enjoyed without fear or reproach.

The robust science that has brought strong evidence to support this is to be celebrated. More than ever before, we now have within our hands the opportunity to counter both perceived and experienced stigma and really embrace the fact that when individuals know their status, link to antiretroviral therapy and become virally suppressed then life can return to normal in the fullest sense.

I commend to you this resource and I applaud all of those involved in its creation.

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Immediate Past President, International AIDS Society.

“U=U is the future, [if we can talk about it in its totality] it can liberate women from discrimination and from the awful laws around HIV transmission”

KENYA



Foreword

Since its announcement, Undetectable equals Untransmittable (U=U) has become a call to action to assert that when someone living with HIV has an undetectable viral load they cannot transmit HIV. Additionally, the U=U message is evolving to challenge notions of HIV infectivity, vulnerability and stigma.

The science behind the U=U message provides the evidence that we can reduce the anxiety related to the sexual transmission of the HIV virus with confidence.

To contribute to getting this message out, ICASO produced a Community Brief on U=U (Oct 2017) and this brief follows on from this endeavor and looks at U=U in relation to women living with HIV. In particular, this community brief aims to capture the voices of women from around the world living with HIV. Their voices illuminate the intensely personal experiences of pregnancy, motherhood and infant feeding as well as some of the nuances around sexuality, access, equity and gender which exist in the lives of women living with HIV.

Our goal was to ask women living with HIV about their understanding and experiences related to the U=U messaging to date, to not only answer questions, but to also raise other important issues that require further deliberation, consultation and conversation.

As such, this brief contains the voices of women from around the world and we have used the country of origin of the speaker (as opposed to a single person) to highlight the shared sentiments among women across the globe.

This community brief was written by a team of women living with HIV and was guided by a global community advisory committee, also made up by women living with HIV. Together we collected stories from over 65 women living with HIV from around the world and held two community consultations in Amsterdam in July 2018.

This community brief acknowledges our diversity as women living with HIV, which includes transgender men, gender queer people and others identified female at birth. Our team felt it was important to indicate this inclusivity in this brief by using an asterisk * where our diversity is included.

To the women* who shared their experiences and intensely personal understandings of U=U through this project we thank each and every one of you.

This brief concludes with four actions that we as women* living with HIV believe need urgent attention. We acknowledge and appreciate that U=U is providing a platform for women* to have a voice that respond.

We are women* living with HIV and ...

we are mothers, young women, post-menopausal women, lesbian and queer women, sex workers, women who use drugs, Indigenous women, women with disabilities, transgender men, young women who were born with HIV, women from diverse geographic locations, languages, religious faiths and ethnic groups with varying education, employment and socio-economic statuses.

U=U: What Does it Mean?

U=U in the simplest of terms, means if someone living with HIV is determined to be undetectable (based on their laboratory results) then the virus is not transmittable through sexual activities. Evidence is clear that a person who is on antiretroviral therapy and has sustained an undetectable viral load for at least six months, they cannot transmit the virus through any sexual activities. A global consensus statement first launched in 2016 by the Prevention Access Campaign (U.S.) sparked a global movement to change public opinion on HIV transmission and challenge the stigma that people living with HIV continue to face around the world.

“The world would be a better place to live in if everyone was virally suppressed, simply beautiful.”

RWANDA



How U=U Impacts Women* Living with HIV

“Having information is having power, and as women living with HIV, we want to have the right and the power about our own sexuality and about our bodies. We want to receive updated information about breastfeeding and we want to be respected for the decisions we make about the autonomy of our bodies. Deciding how and when to give birth is our right

BOLIVIA



The term U=U is evolving to be increasingly broad and inclusive, and it is supported and celebrated by numerous organizations, including groups of women* worldwide. While most early adopters of the statement were organizations based in the Global North, where people living with HIV commonly have better access to treatment, the message quickly spread to developing countries and rural communities, where access to treatment may be limited or of a lower quality. However, because the current application of U=U is focused on the risk of sexual transmission, conversations about the other ways that HIV is transmitted and uniquely impacts the lives of women*, many of which are linked to their sexual and reproductive health and rights and are much more complicated in the current global dialogue.

For many women*, pregnancy and breastfeeding are two key areas that need to be brought forward in the current U=U discourse. These are two aspects of some women's* lives that need to be addressed in any conversation about U=U. This may be due to

assumptions they may make when they first learn or receive information about U=U (e.g. that it includes risks associated with pregnancy and breastfeeding). But regardless, the widespread adoption of the U=U discourse provides an important opportunity to ensure that the sexual and reproductive rights of women living with HIV are recognized in the context of U=U as an advocacy tool for women* living with HIV and their service providers.

Importantly, the profile of the U=U message has the potential to be a catalyst for the **much-needed conversations** about gender inequalities and violence, women's* self-determination, access to treatment, women's* involvement in research, body autonomy and informed choice as essential aspects in the lives of women* regardless of whether or not a woman* living with HIV is undetectable. The transformative and liberating nature of the **U=U messaging for women* could be even more relevant** beyond the context of sexual relations if we consider these aspects in women's lives

1.

Sexual Health

Women* living with HIV have the right to self-determination and the power over their own bodies and to be supported to make informed decisions in regards to their sex lives and their sexuality.

There is clear evidence that supports the U=U message that a woman* living with HIV who has an undetectable viral load cannot transmit HIV to a sexual partner. In 2008, a controversial statement was released that suggested that people living with HIV who were on treatment with an undetectable viral load and without other sexually transmitted infections, could engage in condomless sex as a method of conception. This was known as the

The Swiss Statement.

While there is an ever-growing body of research to support the evidence of U=U, it was the HIV Prevention **Trials Network 052** (HPTN 052) that reported in 2011 that the risk of transmission is dramatically reduced if a person living with HIV is on effective treatment. Updated findings in 2016, indicated that there were no cases of transmission between heterosexual couples having condomless sex, when the person living with HIV was undetectable.

"U=U means we get to enjoy sexual pleasure either with condoms or without, when it is agreed between couples"

ARGENTINA

"With U=U our sexual life is much better. There is no fear of becoming a source of infection for your partner. These days, I do not worry about my status if I am having casual sex."

ESTONIA

"As a sex worker, it's the ideal answer to enjoying sex with your partners and your clients"

RWANDA

"It allows women to be free to explore their sexuality without fear or prejudice. It boosts our confidence, we get to enjoy sex more and eliminates the self-stigma that we often carry around with us"

KENYA

"U=U means that I may be able to go out with a guy that is good enough for me - I date down [or settle for bad relationships] because I feel these men are usually willing to accept my HIV status"

CANADA

"In my personal life, most of the time when my partners are negative, I notice some fear in their eyes. They have never been adequately informed about U=U and that it is the truth and has evidence. They follow the same stigmas they have always believed in and it is very difficult for them understand that this is possible"

CHILE

In addition, the **PARTNER studies** reported over 44,000 (2014), 58,000 (2016) and **77,000** (2018) condomless sexual acts (vaginal and/or anal) among study participants in sero-different relationships (where one partner was living with HIV and was undetectable) and found that there were no transmissions of HIV.

U=U means that women* living with HIV that are undetectable can explore the sexual relationships and practices they want with the confidence that they will not transmit their HIV to their sexual partner and fully enjoy the pleasures of oral, vaginal and anal sex. **The risk is zero.**

However, what U=U does not currently highlight in addition to sexual behaviors, is a woman's* sexuality and her right to express it in the context of living with HIV.

For far too long, it has not always been possible for women* to negotiate condom use due to common gender-based power dynamics, including both real and perceived violence and access. This has meant that negotiating condom use has not always been easy or straightforward and at times impossible for women*. While in many ways U=U gives the impression of sexual freedom; many women live in societies and communities that do not condone or support a woman's* right of sexual freedom.

Sexual risk for women* implies more than sexually transmitted infections. One obvious biological difference is that vaginal sex without a condom can have very different results and implications for women* than men (or those born without a uterus), because women* can become pregnant (both wanted and unwanted) which carries the weight of preventing vertical transmission.

In many countries around the world, people living with HIV can be criminally charged for the possible exposure of HIV to a sexual partner regardless of their viral load.

This is known as **HIV criminalization**. **Women in particular are at risk** of becoming a victim of these discriminatory laws due to the erroneous assumption that women are more likely to know their HIV status and in turn more likely to be blamed for bringing HIV into the relationship.

"There is something that strikes me as odd, it is this generalized "fear" of oral sex [on women] even if they know that I am undetectable. I have never been told this, but I perceive it, because the moment I disclose, oral sex becomes more mechanical. And that bothers me a lot, because my pleasure seems that it does not matter"

COSTA RICA

"Men have always been more scared of me because of my HIV and now that they are not, I feel I need to reconsider my previous reproductive choices"

JAMAICA

"Ever since I started to feel comfortable about not using condoms with my partner, I have had two unplanned pregnancies. When I went for an abortion, I asked the doctor to give me an IUD. They said that they would not perform the procedure, because I was an HIV positive woman and I should not be having sex and certainly not without condoms"

CANADA

"Many women still have "fear" that when having sex, they will transmit the virus to their partner so they only use condoms. They do not understand that your viral load is just as important"

PERU

Pregnancy¹

Women* living with HIV have the right to self-determination and the power over their own bodies and to support to make informed choices in regard to pregnancy and childbirth.

Research from over two decades ago demonstrated that when a woman* living with HIV is virally suppressed prior to contraception and remains undetectable throughout their pregnancy there is virtually no vertical transmission of HIV from a mother to her infant.

Our bodies were the first testing grounds to demonstrate U=U (although not described as U=U at the time).

In 1996, women* living with HIV were the subjects of the **first research studies** that showed a 66% decrease in transmission when treatment was used as the prevention from mother to child.

Providing women and their infant AZT during labor and delivery became the backbone of all early Prevention of Mother to Child Transmission (PMTCT) programs globally. PMTCT has been updated and is commonly referred to as the Elimination to Mother to Child Transmission (EMTCT). However, Vertical Transmission is the term that many community members prefer because it does not place blame on women* living with HIV who have or may give birth. Early commencement of treatment has impacted

“U=U gives us one more argument as a woman living with HIV to realize our right to motherhood. Despite the facts proved many years ago, that women living with HIV who have an undetectable viral load, can bear healthy HIV negative children, we still face discrimination with regard to our reproductive rights. we must include information about U=U in all consultations concerning sexual and reproductive health. Being undetectable eliminates transmission risks in discordant couples who want to conceive a child. This is an opportunity to conceive a child naturally, which means putting all your love and tenderness into it”

KAZAKHSTAN

“It affects women in relation to motherhood, giving them the possibility of giving birth without the risk of passing on HIV through a vaginal delivery”

PATAGONIA

“We knew in the nineties that women who were on treatment could prevent vertical transmission to their children. We knew and created U=U before it was ever a thing, but because we were women no one listened to us”

CANADA

¹ Includes both (vertical transmission/PMTCT programs)

women* who want to become pregnant and give birth by providing them with an assurance that a vaginal birth is not a risk to their unborn child.

Women* living with HIV who are virally suppressed are often free to choose the method of delivery they desire. In some cases, they also have access to support programs that strongly recommend that women* living with HIV have access to treatment prior to their pregnancy and after their child is born. This is based upon the body of research that clearly demonstrates that healthy mothers have healthy families.

Although there have been important strides for pregnant women* living with HIV that has resulted in a nearly 0% chance of **vertical transmission** when a woman* has been on treatment before and during the birth of her baby. We encourage an expanded U=U dialogue that includes of the importance of applying the U=U message to the complexity of choices associated with pregnancy.

Without question, the U=U message has direct relevance to the very important life experience for women* globally who want to become pregnant and give birth. The U=U campaign has the volume to make our voices heard.

The misconceptions that women* can have sex and have a baby and everything will be fine is both true and not. While babies are born without HIV to women* living with HIV without treatment intervention, the dominant view is that women's* bodies continue to be seen as the conduit of potential transmission to their children and our choices about treatment commencement and interruptions are often taken away from us.

Women* living with HIV are profoundly impacted by the HIV stigma and discrimination that continues to exist across health care settings and communities in every nation. The U=U message provides a challenge to the undue, unnecessary and **constant surveillance and correction** by health care workers of the bodies and choices of women* living with HIV.

“U=U gives a mother a relief from the fear and a feeling of peace, because they know they won’t infect their baby”

RWANDA

“It gives us the security of exercising the right to motherhood without fear and without guilt”

COSTA RICA

“There is now no fear of natural conception, of transmitting the virus to the baby during pregnancy or when breastfeeding. It makes universal vertical transmission a reality. We can enjoy motherhood like any other mother and the assurance that baby will be born negative”

KENYA

“For me, this is the confidence in the future and the actual and clear confirmation of the safety and health of my husband and children”

UKRAINE

Understanding U=U for women living with HIV

SCIENCE

The lives of women* living with HIV must be included in the development of the scientific evidence that continues to support the U=U message.

SEXUAL HEALTH

Women* living with HIV have the right to express their sexuality and to have sex in ways that feel good to them.

PREGNANCY

The concept of U=U was proven in the bodies of women* living with HIV seeking to avoid vertical transmission. This history must be honored and respected.

IMPACT

U=U impacts women* living with HIV in multiple ways and all of these must be appreciated and addressed.

LAW

All laws that criminalize women* living with HIV must end. U=U is a powerful tool to make this happen.

CONVERSATIONS

U=U provides a supportive platform to talk about gender and HIV, infectivity and risk and all the additional choices women* living with HIV have in relation to reproductive health.





POWER

The U=U movement must rally to support women's* rights and gender equality.

TREATMENT

Women* living with HIV must have access to the full range of treatment options that exist both for themselves and their families.

DIFFERENTIAL ACCESS

Women* living with HIV experience access to treatment and care differently around the world. The benefits of U=U will never be fully realized until the inequity of access is addressed and solved.

BREASTFEEDING

Women* living with HIV must be supported to make the best choices regarding infant feeding. Including more research on breastfeeding and vertical transmission.

SURVEILLANCE

The undue scrutiny and control over the sexual and reproductive health and rights of women* living with HIV must stop.

INFORMED CHOICES

U=U has demonstrated that knowledge is power. Women* living with HIV have the right to the best information available so they can make informed decisions for themselves and their families.

Breastfeeding

Women* living with HIV have the right to self-determination and the power over their own bodies and the support to make informed decisions in regards to infant feeding. In 2016, the World Health Organization (WHO) guidelines recommended that mothers living with HIV should exclusively breastfeed their infants for the first six months of life and continue to breastfeed while complementary foods are introduced until 12 months and potentially beyond. This is while also having access to anti-retroviral therapy (ART) and counseling support for the duration of both the pregnancy and breastfeeding. However, the WHO guidelines are directed towards developing countries where clean drinking water may be difficult to access. For many developed countries the suggestion is to follow country guidelines which, in many cases, does not condone mothers living with HIV to breastfeed their infants.

There is mounting evidence that the rate of transmission of HIV through breastfeeding for women who are on ART and have a stable undetectable viral load are extremely low and, in some studies, as low as 0.3 to 0.7%. A recent study in Tanzania reported that women in the study with an undetectable and fully suppressed viral load did not transmit HIV to their infant. Importantly, continued monitoring of numerous cases across many developing countries emphasize that women* living with HIV who are supported by their health care providers do not pass on HIV to their infant during breastfeeding.

“I understand in fact, you can breastfeed until the child begins to eat solid foods. And with regard to childbirth it can be practiced naturally, with no danger of infecting your baby”

ARGENTINA

“What? You are not allowed to breastfeed in North America? I don’t understand? All women living with HIV in Africa do and it is what makes the baby strong and healthy”

KENYA

We encourage all those supporting the U=U movement to support women* living with HIV to better understand the risks of HIV transmission via breastfeeding.

There is an urgent need to recognize the social, emotional, practical and cultural challenges that women experience when it comes to the pressures they are under to breastfeed or not.

For many mothers living with HIV, there continues to be a disconnect between medical evidence, breastfeeding guidelines, cultural practices and public health approaches to the risks and harms in relation to breastfeeding. Importantly, there is also the community discourse on breastfeeding, which in many cases has resulted in an underground network of mothers living with HIV who support and advise each other using anecdotal evidence and story sharing as its main source of peer review.

What is most concerning is the fact that there is a fear on the part of women* living with HIV that they will not receive all the information on breastfeeding, nor will they receive appropriate social or medical support if they express their desire to breastfeed. This is both troubling and concerning. This prevents women* living with HIV from having the information they require to make their own informed decisions and choices that may affect the future health of their children and families.

The U=U movement needs to advocate for women* to have full access to the information and presumed risk of transmission during breastfeeding and the **access to the treatment as well as adherence support.** Women living with HIV will continue to access peer to peer messaging which may be different from what is supported and practiced in their country of residence. In the worst of cases, children are separated from their mothers and in extreme situations being women* living with HIV are being **criminally charged**, devastating the mother, the child, their community and subsequently adding more fuel to the HIV stigma and discrimination felt by women* living with HIV worldwide.

"I never told anyone how deeply I wanted to breastfeed. I did it in secret because I knew it was the best thing for me and my baby"

AUSTRALIA

"It would totally change the lives of women who want to be mothers and especially when it comes to breastfeeding and being able to feel the connection between mother and child"

ARGENTINA

Barriers for applying U=U to women* living with HIV

At its core, the application of U=U to any person living with HIV relies upon knowing and being certain that your viral load is undetectable. However, women* living with HIV face additional hurdles and barriers which often delay or deny their equity of access to viral load testing which would improve their lives.

Women* experience HIV and access to treatment, care and support differently as a result of power and gender inequalities.

The U=U discourse must include women* living with HIV and address not just their sexual rights, responsibilities and freedoms but also the other aspects and concerns that women* living with HIV have to face.

The U=U movement is shifting the narrative of what it means to be living with HIV in the 21st century. However, the achievement and maintenance of an undetectable viral load requires that fundamental and basic rights are achieved. So long as there is unequal access to treatment, care and support, as well as unequal access to economic security, freedom from violence and access to reproductive choices, women* living with HIV will always have their lives and the wellbeing of their families compromised.

“Young women and mothers living with HIV have a lot of issues to deal with and when it gets to motherhood it gets worse, sometimes it becomes too much to handle and they end up skipping their meds”

RWANDA

“In my culture, women are the main caregivers of the children and sometimes the only caregiver in the family. We do not have the time to take care of our own health, we forget to take the medication on time or even go to the clinics to get the HIV treatment”

ARMENIA

“I am a young woman infected through vertical transmission and although I have been taking medicine for many years I have serious problems with my adherence due to my depression”

PANAMA

“The main barrier is the lack of access to quality treatment, which includes the appropriate legal environment and gender equality which should support it”

UKRAINE

“Violence and poverty are two factors, together or separately, that influence not achieving undetectability”

HONDURAS



“Being undetectable is seen as something hard, a real challenge to achieve, so a number of people in my life just gave up before they even started”

UNITED STATES



“Women in my community don’t have access to the basic necessities, so I don’t think that they are even caring about U=U. Their kids and family come before their personal trips to the clinic to get treatment and to maintain an undetectable viral load”

NEPAL



“As soon as women with HIV cease to be seen as a source of infection, this will significantly reduce the stigma towards them”

UKRAINE



“Married women will not achieve viral suppression without the support from their spouses”

RWANDA



“Often when I try to bring up worrisome symptoms that I’m experiencing in relation to being trans, their go-to is “yeah O.K., but you’re undetectable, and that’s what’s important”, and it’s discouraging.... it’s like my total health doesn’t matter it’s just about being undetectable”

CANADA



Strengthening the U=U messaging for women living with HIV

“U=U is for young people and excludes women who are older and long-term survivors. How do you expect a woman who has been told for 20 or 30 years, that they should not have sex to suddenly say – oh great now I can finally date and not wear a condom. It doesn’t work like that”

JAMAICA



“It is very important that the information on U=U is distributed widely across all countries. It will help eradicate stigmatization and free us from the sexist and institutional violence directed at us. We can decide on our body and our motherhood... we need sex education from the first school stage, a lot of awareness, free and good treatments and obviously a cure”

ARGENTINA



“In my country, we are told not to breastfeed our children and forced to purchase formula which is very expensive. But, during the earthquakes we didn’t have access to clean drinking water and many women living with HIV had to breastfeed their children. This was a horrific experience for women as we were in an emergency and at the same time we felt like criminals”

NEPAL



“I want the U=U movement to work more with religious leaders to educate them on HIV and transmission...to stop HIV being a barrier to marriage. We are good women and have the right to loving relationships”

MALAYSIA



"For me, this is an opportunity to use scientific evidence to abolish the criminalization of HIV, which makes HIV positive people criminals"

UKRAINE



"There is a large majority of women with HIV who do not have this information, because the health workers deny them access, so we have as a result the constant violation of sexual and reproductive rights, the violation of the right to autonomy of our bodies and to decide how and when to give birth"

ARGENTINA



"Outreach and communication campaigns are essential to educate the population and sensitize health personnel to generate an environment of trust and promote these rights. We must generate campaigns that allow us to influence public opinion, to sensitize and get more people with HIV (and their friends and family) to understand that we can live long and healthy lives, have children and never have to worry about transmitting our infection to others"

COSTA RICA



"They tell us that we need to use condoms because we cannot adhere to our treatment, but at the same time they make us breastfeed because they say we are on treatment. The message from health care providers in Africa is unclear, patronizing and unsupportive to our decision-making process"

KENYA



Take action to improve the lives of women living with HIV



Support our right to make informed choices about what we do with our bodies and our right to celebrate sexual pleasure as women* living with HIV. Advocate for our sexual and reproductive rights, including the right to the birth control options of our choice as well as access to safe and legal abortion.



Appreciate that women's bodies are part of the foundation of what we now know as the U=U movement. Demand better research into vertical transmission in the context of U=U.



Support women* living with HIV to make informed choices about breastfeeding. Provide us the freedom to make the best decisions about infant feeding options for ourselves and our children and respect our decisions.



Increase, improve and guarantee access to the range of HIV treatments that work best for us as women* living with HIV, for our children and for our families. Let's reach 100-100-100.