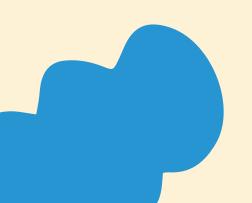




Using U=U to Take Ownership of Our Lives and Our Futures: Stories Written by and for Young People Living and Affected by HIV

EGPAF's Committee of African Youth Advisors

Lira and Obi



Acknowledgements

We would like to recognize the Elizabeth Glaser Pediatric AIDS Foundation's Committee of African Youth Advisors (CAYA) teams — consisting of young leaders (CAYA members), focal points, and global team members — in their tremendous efforts, ideas, and support in developing this resource.

CAYA Members: Merveille Mulema — Democratic Republic of the Congo, Chadrack Mudikisi — Democratic Republic of the Congo, Tanya Vinho — Zimbabwe, Rosa Mahlasera — Zimbabwe, Gilbert Mitti — Malawi, Vanessa Mpakati — Malawi, Olicio — Mozambique, Aghostinho — Mozambique, Ismail Harerimana — Uganda, Asiimwe Bena Odeta — Uganda, Joshua Ochieng — Kenya, Saline Awour Mboya — Kenya, Lulu Emmanuel — Tanzania, Erick Bryson — Tanzania, Mthobisi Simelane — Lesotho, Temahlungwane Mkhonta — Lesotho, Franck Koffi — Côte d'Ivoire, Arnaud — Côte d'Ivoire, Achu Eric — Cameroon, Loh Lionelle Nelend Deborah — Cameroon

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CAYA Global Team: Cosette Audi, Lauren Greenberg, Mark Prunella-Miller, Sara Denison-Johnston, Eric Bond, Madeline Morris

We would like to thank Kelsey Brosnan, designer extraordinaire, in creating a fun, creative, and fresh way to capture the full story collection as a complete resource.

We would like to recognize the contributions of the technical team from the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) in supporting the development and review of the resource.

EGPAF Technical Staff: Cosima Lenz, Leah Petit, Dr. Judith Kose, Dr. Natella Rakhmanina, Brain White

We would also like to recognize the team from the Accelerating Achievement for Africa's Adolescents (Accelerate) Hub for their contributions and support in creating the stories.

Accelerate Hub Team: Dr. Elona Toska, Angelique Thomas, Chelsea Coakley

We would like to acknowledge the graphic design team from Urithi Studios for their brilliant designs in bringing these CAYA stories to life.

Urithi Team: Isaac Kauye, Joseph Kalwanyi, Diana Bwengye, Trina Ribanakisuyi

We would like to thank ViiV Healthcare and ELMA Philanthropies for providing the financial support to enable the development of this tool.













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Introduction

This tool is a collection of three, short graphic stories focused on different scenarios where U=U (undetectable equals untransmittable can apply to the lives of young people living with or affected by HIV.

Young people from across Africa were leaders in the conceptualization, design, writing, and validation of this tool. The goal of the story collection is to provide a practical resource for young people and providers working with young people to talk about U=U in a way that makes sense and applies to regular situations that happen in young people's lives.

Why we created this tool:

U=U is a concept that has been shared most frequently through different messages over social media and different campaigns to empower people to keep taking their medication in gaining power and control over their lives to not transmit the virus once reaching the undetectable level.

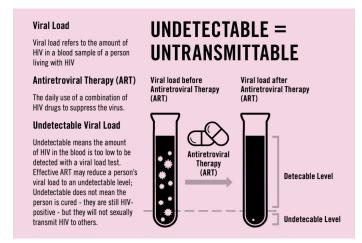
Before we started to create this tool, we looked at the types of resources on U=U for young people globally and across the African continent. We found no resources that applied U=U to real life scenarios of young people and explained it in a way that would make sense to young people.

U=U can be a complex topic to talk about and understand. A few concepts are critical to understand that accompany U=U, including viral load, viral load suppression, and adherence.

What is U=U?

U=U stands for Undetectable = Untransmittable for sexual relations. Being Undetectable is when someone who is living with HIV — and on antiretroviral therapy (ART) — and has a viral load that is so low that it is barely detected (a very small amount or none detected) during the viral load test. Once the amount of virus is under a certain level, the virus is Untransmittable. This means it CANNOT be passed sexually to another person.

Undetectable: The levels for viral detection are often as low as 20 or 50 copies per milliliter (mL)



in a viral load sample. Having a viral load under 200 copies per mL for at least six months is undetectable for sexual transmission. For prevention of mother to child transmission, the level for preventing transmission is lower at less than 50 copies/mL.

Untransmittable: Not spreading or transmitting the virus to a sexual partner

Figure 1. U=U infographic1

¹ http://actupdublin.com/2017/04/28/undetectableuntransmittable/

De-coding viral load

Sometimes, it can be hard to understand when a health care provider (such as a doctor, nurse, pharmacist, adherence counsellor) is explaining the results of a viral load test. We attempt to translate some things you may come across here and how they relate to U=U.

What you might hear a health care works say	What this actually means and how it relates to U=U
"Your viral load is undetectable"	The sample of blood from the viral load test was looked at using laboratory equipment sensitive enough to see the number of virus copies in the blood.
	An undetectable viral load result means the number of viral copies (HIV) is less than the threshold used by the laboratory, which frequently is as low as 20 copies/mL.
	For sexual transmission, the undetectable threshold is below 200 copies in every milliliter of blood.
	This is an excellent achievement! It means that the medication you are taking is helping your body to fight and control the virus, and you are taking your medications as prescribed!
	This does <u>not</u> mean you are cured of HIV. There is currently no cure for HIV, but it means the virus is under control. It is critical to keep taking your medication as prescribed to keep the viral level low.
	 When you are undetectable, you CANNNOT transmit the virus to other people through sex, which is what U=U means.
"You are virally suppressed"	A suppressed result means the number of viral copies (HIV) is less than 1,000 in every milliliter of blood in the sample taken during the viral load test
	It is important to know that having achieved a viral load below 1,000 copies required strict regime adherence to avoid it spilling above 1,000
	 Although reaching 1,000 — the suppressed threshold — is an excellent accomplishment, this is not the same as undetectable. In the suppressed range until 200 copies, there is still a risk of transmitting the virus through unprotected sex
	This is also an excellent accomplishment and something to be proud of!
	 In some places, the equipment can only detect up to 1,000 or 500 copies in a viral load sample, and, therefore, it can be difficult to determine if someone is undetectable (<200 copies)
*Important note: different	countries have different guidelines and thresholds for having a high

"You are experiencing treatment failure"

- Sometimes medication stops working, and the amount of virus in the body can increase in response. This is not the fault of anyone.
- The term *treatment failure* does not mean you failed anything nor does it mean you are dying. It simply means it is time to change to a new regimen of medication that can work better to fight against the virus.

"Viral load failure means that you are in a better chance to discontinue with your current regimen and hence there is need to switch to a new regimen. It also gives you a chance to re- strategize your adherence plan through adhering to the new regimen."

— Young leader, Kenya



Getting to undetectable and connecting it to adherence

The most important factor that contributes to becoming undetectable or virally suppressed is taking your medication consistently according to your personal adherence workplan in line with the doctor's prescription. This helps your body have the amount of medication it needs to get the viral level low.

It is normal to experience different challenges in taking your medication daily at the same time. It can be helpful to make a plan based on a changing schedule (weekends, when traveling, or in school, for example). Other tips include connecting the reminder to take your medication to a certain action of the day. This can include:

- Brushing your teeth
- · When the nightly news comes on
- Setting a watch/cell phone alarm
- · When you wake up

If you forget or skip taking your medication, try to take it within a few hours or just start again the next day. Being consistent with a plan is the most important thing. Taking your medication as prescribed is the key to living a long, healthy life so you can reach for your dreams. If you are having trouble, reach out to your provider or peer at your health care facility for their support.

YOU GOT THIS!

What Is This Accompanying Guide For?

This guide accompanies the graphic stories and is designed to provide complimentary information. It also provides guidance for individuals using the story collection with adolescents and young people.

How do you use this guide?

The story collection can be used in different ways including:

- One-on-one counselling:
 - Adult counsellors or peer counsellors can use the stories to read through the narratives together and talk through the key messages to make U=U, adherence, viral load, prevention, etc. more relatable to the young person's life
- Adolescent and youth support groups (virtual and in-person)
 - Different activities in using the stories include:
 - Small group reads
 - Individual reading
 - Role plays
- With subsequent discussions around key messages, Q&A, and clarifications

Who is this guide for?

This accompanying guide is particularly meant for counsellors and peer educators/facilitators/champions who support young people. It provides additional information for productive conversations following reading through the stories and emphasizing key points.

It is helpful for any cadre using this tool to first read through the guide fully and review the stories to be familiar with the contents and messages. When introducing the activity, it is helpful to follow steps similar to those presented below:

- 1. Introduce the story collection
 - a. For example: these stories were created by young people living with HIV from across Africa to share more around U=U in a friendly way and show how it can be applied to different, realistic scenarios we may find ourselves in throughout our lives
- 2. Introduce how you will use the story collection:
 - a. For example: You can choose which story we read through today and how we use it. We can...
 - i. break into small groups and read it together or
 - ii. select different people to play a different character and do a role play in front of the group or
 - iii. read it individually or

- iv. have one person read it aloud in front of the group
- b. b. There are three stories within the collection. One is focused on disclosure in a relatively new couple between a young woman and young man; the second focuses on a young woman finding out she is pregnant and sharing with her partner; the third focuses on disclosure and prevention in a relationship between two young men
- 3. Read/act through the stories
- 4. Talk about the stories and link them back to the realities of young people's lives
 - Each story has accompanying questions that can help spark discussions, but feel free to encourage personal sharing both challenges and solutions individuals have faced
- 5. Thank everyone for sharing and participating in the activity

The Story Collection and Discussion Guide

There are three stories in the current collection, each with unique characters and focus:

- Story #1: Lira and Obi
- Story #2: Martha and Ibrahim
- Story #3: Junior and Tambo

The next portion of the guide has separate guidance for each story with detailed messaging and discussion questions that are meant to accompany each story.

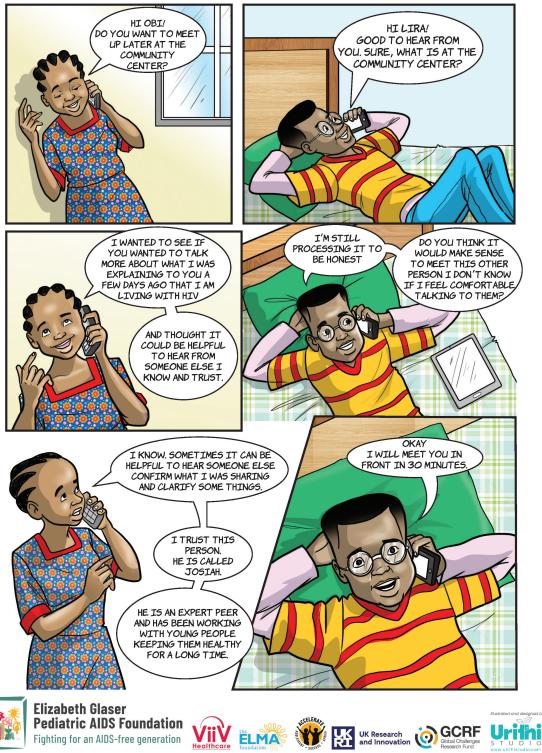
Steps in using the stories as part of a group activity:

- **Step 1.** Introduce the story
- Step 2. Discuss and agree on how the group wants to do the activity
- Step 3. Read/act the story
- **Step 4.** Review the discussion questions and answer any questions
- **Step 5.** Invite participants to share any personal experiences of challenges similar to the story. *Ensure a safe and confidential environment where anything shared in the group stays within the group.*
- **Step 6.** Highlight the key messages and takeaways of the story
- Step 7. Thank participants for their engagement and for sharing

Story: Lira and Obi

Story context: This is a story about Obi and Lira. They met a month ago at a party where they spent the entire evening dancing the night away. They have been meeting and talking regularly since that time and started dating. Recently, Lira also disclosed to Obi that she tested positive for HIV when she was born because her mother had been living with HIV. She's always been on treatment and knows that by staying on treatment the amount of virus in her blood remains so low, it is undetected. This was also confirmed at her recent doctor's appointment. Lira asks Obi to come along with her to meet a peer supporter at the community center so she and Obi can find out more information together. They start by telling the peer supporter about their situation (what they are experiencing, what they feel, what their concerns and fears are related to U=U).

LIRA AND OBI









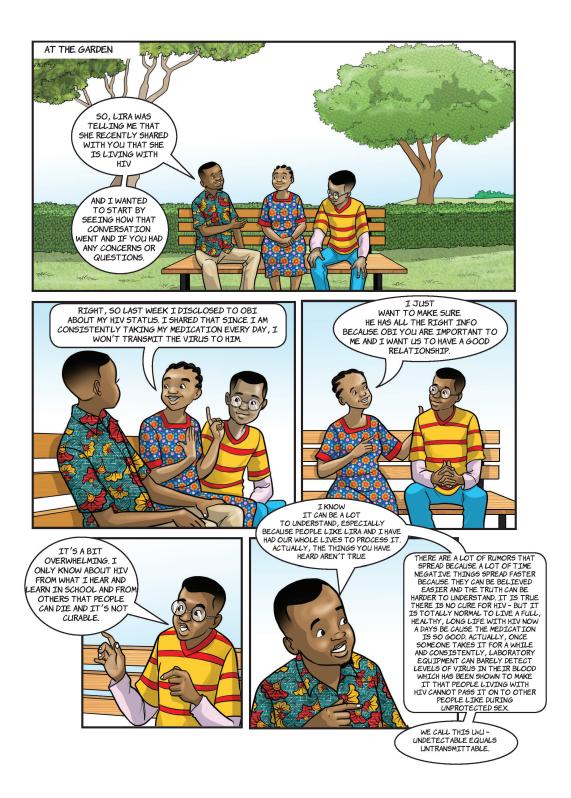


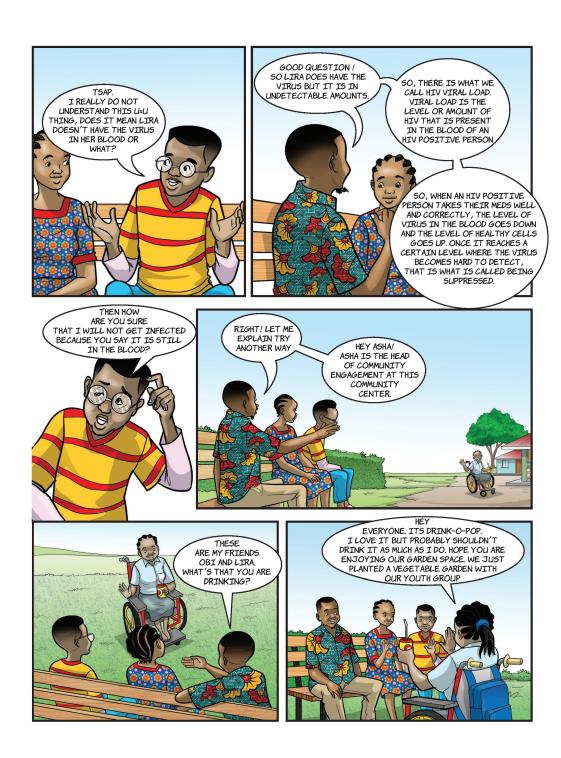


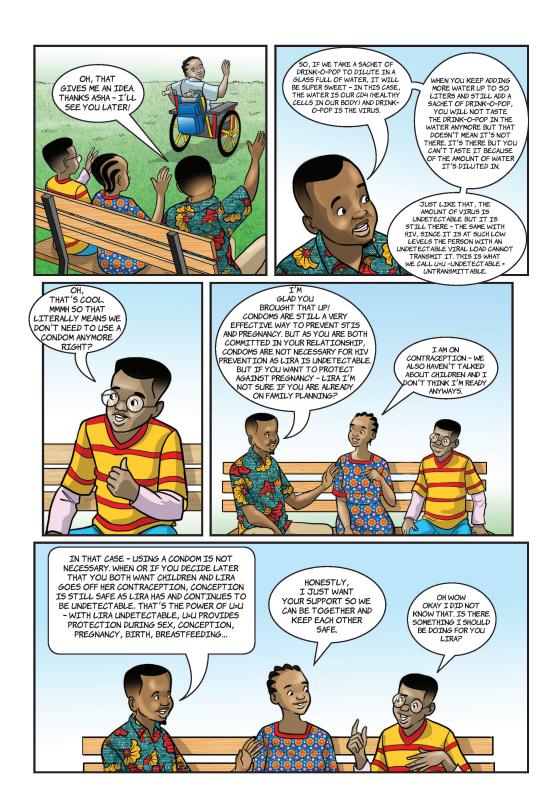


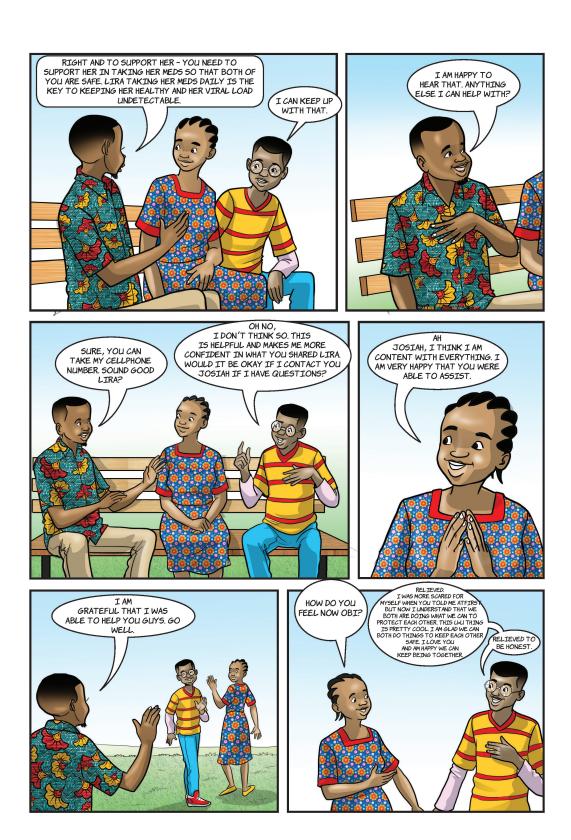












Following the reading of the story, here are a few discussion questions to get the group talking:

- 1. What happened in the story?
- 2. How did Obi's feelings change from the start of the story to the end of it?
- 3. Why did Obi's feelings change? What was said or shared?
- 4. How was U=U explained? Does it make sense?
- 5. How did U=U affect Obi's change of feeling?
- 6. Is this scenario with Lira sharing her status with Obi familiar to anyone? Would anyone like to share?
- 7. Was there anything that surprised you in the story?
- 8. Was anyone surprised when Josiah shared that because Lira is undetectable, Obi and Lira don't need to use a condom if Lira is using family planning? Is there any confusion about that?
- 9. Does anyone remember what Josiah said about condoms? What about family planning?
- 10. What are the key takeaways from this story? Did you learn anything?

Key messages from the story:

- ✓ Disclosure of HIV status to a partner can be scary, but it can be helpful to seek support from peers who have gone through this process or provide other perspectives
- ✓ U=U refers to the concept that when someone living with HIV has a consistently undetectable viral load, they CANNOT transmit the virus to anyone else for example, through sex without a condom
- ✓ Using a condom during sex is always a safe option because it prevents both pregnancy and sexually transmitted infections/diseases (STIs/STDs) like syphilis, gonorrhea, and HPV
 - o In relation to U=U, you don't need to use a condom to prevent HIV with a partner who you are in a committed relationship with

Key takeaways from the story:

- ✓ People living with HIV can have normal, healthy, full lives including meaningful relationships
- ✓ U=U can be a tool of empowerment and knowledge building in showing HIV status does not define or confine someone or their life
- ✓ U=U can be used in the context of disclosing one's status, if you choose, to help explain to a partner there is no risk in transmission if someone is living consistently undetectable

Key terms from the story:

- Family planning: the ability of a person or a couple to decide how and when they want children; this can take the form of using different contraceptive options, including condoms, injectables, and pills, among others
- Contraception: the prevention of getting pregnant by using a device (condom, pill) or through an act (pulling out)

• Conception: this refers to the actual process of becoming pregnant but more specifically is when the sperm fertilizes the egg

Potential questions and responses

Potential questions/confusions	Responses
What if I don't want to disclose to my partner?	You do not need to disclose to anyone until you decide to do so. It is your decision. There are people who can help navigate the process (like Josiah in the story!). This can be peers, friends, and counsellors. It can be helpful to talk through fears or concerns in making the decision to disclose to a partner and how you can protect each other.
What if I don't trust my partner to be true to me? How does that work with U=U?	If you don't think you can trust your partner or you know your partner is seeing other people, it is the safest option to continue using condoms to protect yourself from other STIs. Even if you have sex without a condom, since you are undetectable, your partner would not get HIV. But if you are not sure as to who his/ her other sexual partners are and don't know their status, to limit exposure of other STIs, it would be best to use a condom every time you have sex.
What if my partner is on pre- exposure prophylaxis (PrEP)? Does U=U still work?	PrEP is a great option for HIV prevention! The daily pill reduces risk of acquisition when exposed to HIV. If you are consistently undetectable, U=U still very much works, and PrEP would just be another layer of protection. While PrEP is for a short time, it is still important to continue with ART so you can stay undetectable and reduce the risk of transmission.
What if I don't know my recent viral load?	The best way to find out your viral load is to get a viral load test. You can get more information from the health care facility. They can usually schedule a test for you and get the results back to you within a short time. Most national guidelines require a viral load test six months after starting ART and then every 12 months after. It is important to have a regular viral load test done and to get your results. Learning about results is important to inform your treatment plan and to see if the medicine is working as it should.
Are there different types of viral load tests?	All viral load tests measure the same thing: the level of virus in your blood. There are, however, different technologies, like point-of-care viral load testing, that provide results on the same day without needing to come back to the health care facility to learn your results. Conventional viral load testing requires a bit more time for the sample to get tested at the laboratory — it is important to return to the health care facility to learn your result.

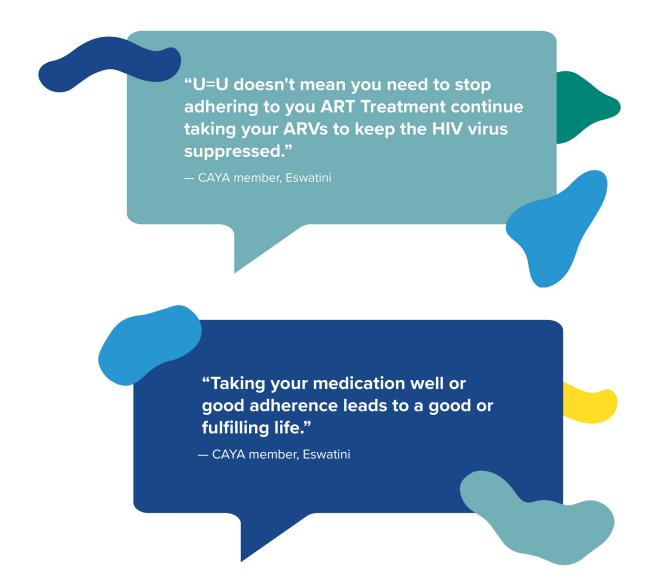
What if there are no viral load tests available?	Sometimes, the stock of supplies for viral load testing can get low, which is a challenge that limits availability of the tests. The best thing to do is to continue taking your medication as discussed with your provider consistently and daily. Your provider will let you know when the supplies are back in stock, or you can ask about it the next time you are at the health care facility. If you are experiencing any side effects or symptoms from the medication, then make an appointment and talk to a health care provider, who can help make a plan to address this.
What if I don't know my partner's status?	One option is to ask if you feel comfortable doing so. If not, that's alright as well. The best way to protect yourself if you don't know your partner's status is to use a condom every time during sex. If your partner is HIV-negative and you are both committed and only seeing each other, U=U shows that you can have sex without a condom and be safe. If you want to prevent pregnancy, then using a condom is also a good option Resource: a disclosure tool is linked here that provides some guidance on supporting adolescents to disclose to their partner (starting page 42)
What if my partner is also living with HIV?	If your partner is living with HIV, then it is a good idea to discuss each of your most recent viral load status to understand if both of you have reached undetectable status. If your partner's viral load status is not undetectable (meaning they are either only virally suppressed or detectable), the safest option would be to use a condom. Sometimes, HIV re-infection can happen, which is when someone living with HIV transmits a different strain of the HIV virus to someone who is already living with HIV. If both you and your partner have undetectable viral loads, there is no risk of transmission. It is important to just continue to support one another to achieve and maintain an undetectable status.
Does U=U apply to all types of sex?	Yes. There is no risk of transmission if you are undetectable with your sexual partner, whether you have vaginal, anal, or oral sex.

How do we know U=U even works?	There have been several, large studies with couples — one person living with HIV and one not living with HIV. The people living with HIV were consistently undetectable and showed they did not transmit to their partners even during condom less sex.
What are viral load blips?	Viral load blips are short episodes when someone's viral load can increase for a short time from undetectable to detectable, for example, even if they have not changed their adherence. This is not a sign that their treatment is longer working, as their viral load usually goes back to being undetectable after a short time.
Do U=U and PrEP protect against all STIs and STDs?	U=U and PrEP are both forms of prevention specific to HIV but NOT other STIs and STDs. Other STIs and STDs, for example, include syphilis, chlamydia, and gonorrhea, which can affect both males and females and can be serious if not treated. Using condoms is effective to protect against STIs and STDs. Health care facilities can also support testing and treatment of STIs and STDs if you think you have symptoms, like a rash, pain, and sores in your genital regions. It is important to know that, in some cases, someone may not have symptoms even if they have an STI or STD. Always good to get tested!

More on U=U From Young People

U=U, as shown in the stories, can apply to your life in different ways, but, more importantly, it is a tool of empowerment and ownership of our lives.

U=U shows us that you are and never will be defined by your status and can live full, healthy, and exciting lives with people we love.



Additional Activities

The three activities below are additional activities focused on safe sex and prevention that could be useful in the U=U context.

Activity 1: Let's Talk About Safe Sex

Step 1: Start by asking the group why it is important to talk about safe sex – why does it matter? (examples: avoiding unwanted pregnancies, staying free from STIs, respect for your partner, etc.)

Follow that discussion by asking the group what they think are attributes of safe sex.

Step 2: Create a list of the things mentioned (examples: condom use, verbal consent, clear communication).

Thank the group for providing examples.

Step 3: Explain that you will have a ball and you can use a trash can or a bin on the other side of the room. Everyone will line up to try to get the ball into the bin that is across the room. If they miss, the facilitator will read a statement aloud that they will need to decide if it is true or false. The group members are allowed to ask the larger group if they are unsure.

Statements for the ball in the bin game:

Statement	Answer	Additional information the facilitator will share with the group
Using two condoms at once (double bagging) provides more protection against STIs/STDs	False	Condoms are made to be used only as individual entities. The friction between the condoms can cause it to break. Additionally, you should not combine a female condom and a male condom.
All birth control or contraception options protect against STIs/STDs and pregnancy	False	Only condoms prevent both STIs/STDs and pregnancy
Using an oil-based lubricant or Vaseline with a condom can cause holes	True	Petroleum jelly (such as Vaseline), grease, hand lotion, baby oil, or anything with oil in it. These products can make holes in the condom
You can get an STI/STD from any kind of sexual contact, not just intercourse/penetrative sex.	True	STIs are spread through skin-to-skin contact between the genitals. You can also get an STI from contact with body fluids such as semen, vaginal fluids, and blood (including menstrual blood). This means you can get an STI from vaginal sex, anal sex, or oral sex.
Human papilloma virus (HPV), which causes genital warts and can cause some cervical cancer can be transmitted sexual but also through touching of an infected persons legions	True	HPV can be transmitted by touching (hand-to-genital or genital-to-genital) an infected person's lesions. Genital warts can be found on parts of the genitals (testicles, vulva) that are not covered or protected by a condom. However, warts are not always visible.

There are no prevention options for STIs/STDs aside from using a condom	False	There are other prevention methods, including medication that someone can take within 72 hours that prevents HIV if you were exposed to HIV. Other examples include getting vaccinated for HPV.
Sex is supposed to be pleasurable	True	Yes, sex is meant to be pleasure for both people.
You can have an STI/STD without knowing it or having any symptoms	True	This is true. Symptoms are not the only indication of having a disease. That's why it is important to get tested.
You can only get an STI/STD if you have sex a lot – not only once	False	You can get an STI/STD even if you have unprotected sex just one time. That is why it is important to always protect yourself and your partner and to talk about it before having sex.
You cannot get an STI/STD from oral sex	False	You can get STIs from open sores that can be in someone's mouth for example.
You or your partner can not get pregnant on their period	False	A girl who is menstruating can get pregnant any time a couple has unprotected sex.
The HPV vaccine is only for women	False	Men also can get infect with HPV, which can cause different cancers, including throat cancer. The vaccine can help prevent that. The HPV vaccine was developed to prevent cancers, infections, and pre-cancers and is recommended for adolescents and young
		adults up to age 26, especially if they are sexually active.

Activity 2: Prevention Beyond Condoms

Start by asking the group what type of prevention for STIs/STDs and pregnancy they are aware of besides condoms. Create a master list at the front of the room.

Once you have the list, go through what was shared and provide a bit more information on it. Ask anyone in the group if they are willing to share any information on any item. If something was not mentioned, use the following box as a guide.

Tell the group there will be a matching exercise after to test their knowledge of these other methods.

Option	Information
Family Planning or Contraception	The use of various methods to avoid unwanted pregnancies. There a lot of options available for men and women. <i>(see chart below)</i>
Post-exposure prophylaxis (PEP)	PEP is anti-HIV drug, which someone can take within 72 hours of potential exposure that can prevent HIV infection. PEP can be taken, for example, if someone has unprotected sex with someone who they don't know the HIV status of; if the condom breaks with someone whose status is unknow; or in the case of rape. PEP is NOT needed if you use a condom with someone living with HIV or if your partner who is living with HIV is consistently on treatment. Once they are undetectable — meaning they have such a little amount of virus in their blood because they take their medicine so regularly that viral load tests can't detect them — they CANNOT transmit HIV to a sexual partner.
Pre-exposure prophylaxis (PrEP)	PrEP is a prevention method that people who do not have HIV can take to reduce their risk of being infected. It is highly effective in preventing HIV when the pill is taken daily as prescribed. Remember, condoms are the only way to prevent other STIs/STDs, including syphilis. PrEP can be taken, for example, by someone who is HIV-negative and is in a relationship with someone living with HIV who does not know their viral load; someone who is HIV-negative and has multiple sex partners and doesn't know their status or doesn't consistency use a condom.
Human Papilloma Virus (HPV) vaccine	The HPV vaccine was developed to prevent cancers, infections, and precancers and is recommended for adolescents and young adults up to age 26, especially if sexually active. HPV is a sexually transmitted virus and causes the majority of cervical cancer cases in women, but it can also cause a variety of cancers in men, including cancer in the throat. The vaccine is not only for women. This is a men's issue, as well. By getting vaccinated, you can protect yourself against the virus, as well as your sexual partners.
U=U	U=U stands for undetectable equals untransmittable. It references that when someone living with HIV who takes their medicine regularly and has an undetectable viral load (meaning the amount of virus in their blood is so low it is almost undetectable by scientific equipment) they CANNOT transmit it to a sexual partner, even if they have unprotected sex.
Abstinence	Abstinence refers to not engaging in sex at all. This is an individual choice and one that others should respect.

Activity 3: Matching Game

The Matching Game below can be played in small groups or in one large group.

Using a pencil, write the number of the situation that is connected to the type of prevention method on the line next to the prevention method.

Situation Prevention Method Someone who is HIV-negative had sex with someone and the 1 **Condoms** condom broke and neither of them knows the HIV status of the other A person usually has sex with 2 multiple people and doesn't Contraception always use a condom This couple wants to wait to have 3 **PEP** children and just want to enjoy each other's company for the time being One person in a couple is living 4 with HIV and has an undetectable **PrEP** viral load and the couple has sex without using a condom When a guy wants to keep his partner and himself safe from both 5 U=U STIS and pregnancy, he will use this When a guy wants to build immunity to the human papilloma 6 **HPV** vaccine virus which can cause cancers in both men and women

ANSWERS:

Using a pencil, write the number of the situation that is connected to the type of prevention method on the line next to the prevention method.

