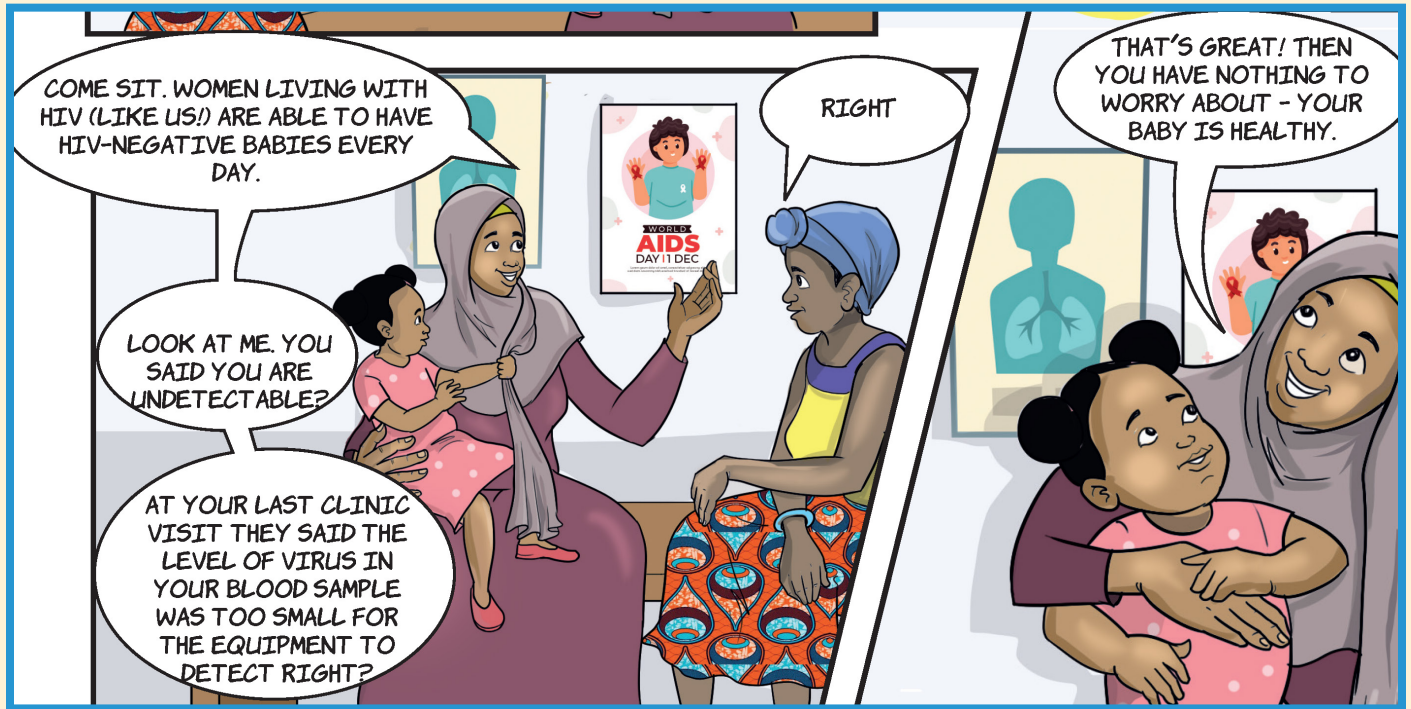




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Pediatric AIDS Foundation**
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Using U=U to Take Ownership of Our Lives and Our Futures: Stories Written by and for Young People Living and Affected by HIV

EGPAF's Committee of African Youth Advisors

Martha and Ibrahim

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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.

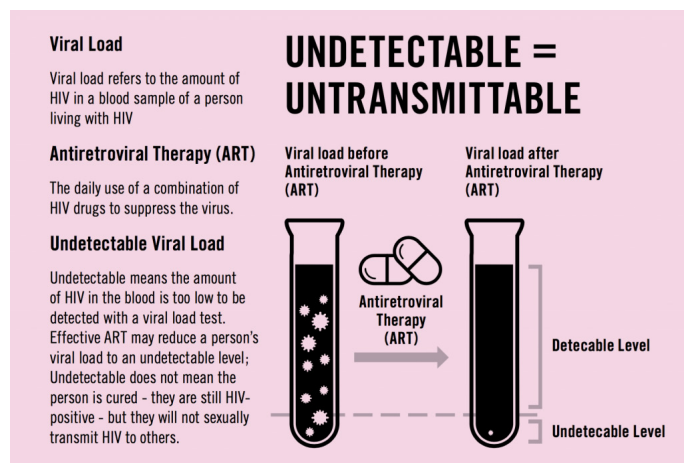
U=U can be a complex topic to talk about and understand. A few concepts are critical to understand that accompany U=U, including viral load, viral load suppression, and adherence.

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
<p>“Your viral load is undetectable”</p>	<ul style="list-style-type: none"> • 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.
<p>“You are virally suppressed”</p>	<ul style="list-style-type: none"> • 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)
<p>*Important note: different countries have different guidelines and thresholds for having a high viral load. In general, when someone has a viral load above 1,000 copies, they are considered to have an elevated viral load and are linked to enhanced adherence counselling and additional support to help make a plan to lower their viral load.</p>	

“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.

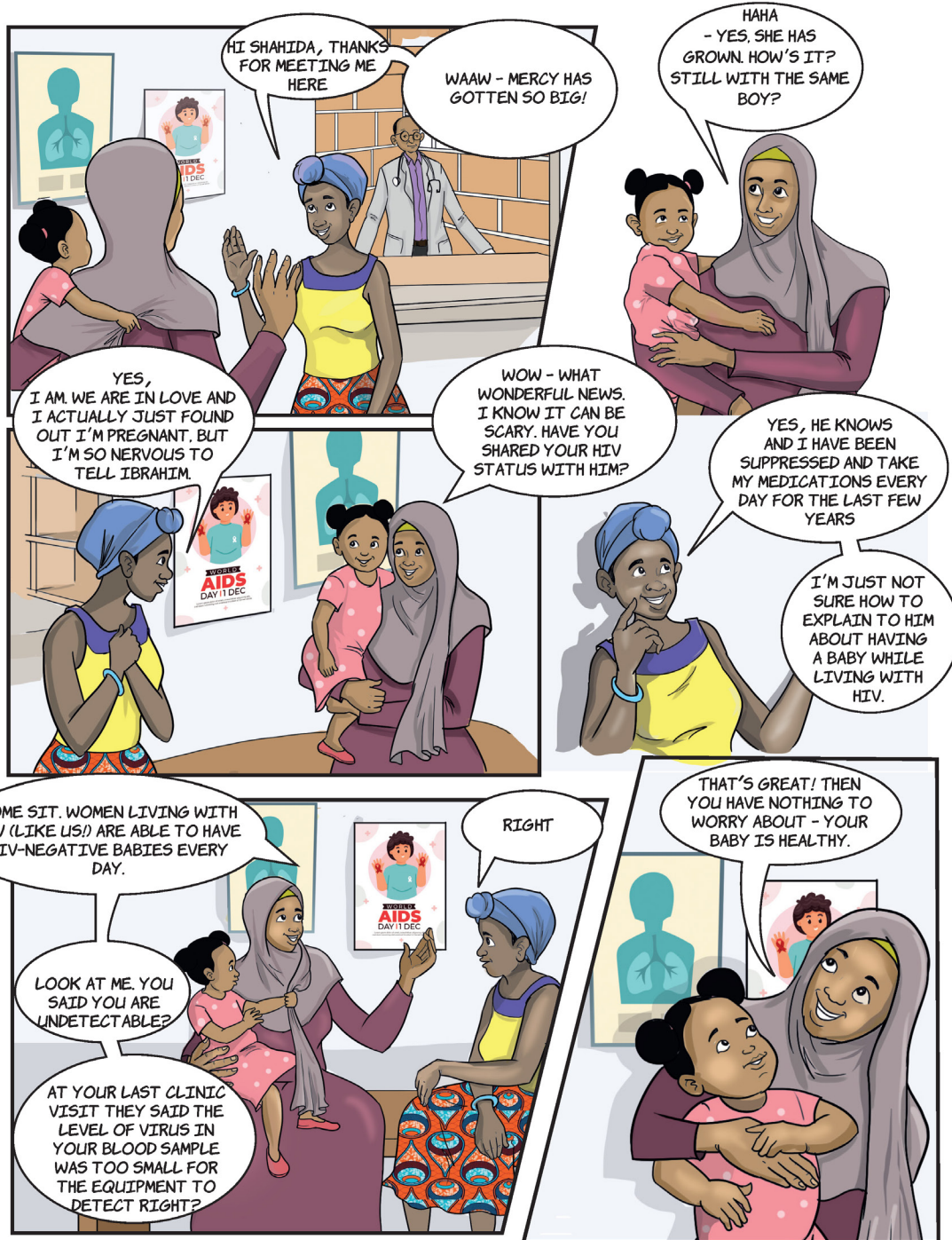
It is helpful for any cadre using this tool to first read through the guide fully and review the stories to be familiar with the contents and messages. When introducing the activity, it is helpful to follow steps similar to those presented below:

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*

Story: Martha and Ibrahim

Story Context: This is a story about Martha and Ibrahim. When Martha was 16-years-old, she contracted HIV. She later met Ibrahim during her tertiary education and told him about her status. Martha explained to Ibrahim how she manages her diagnosis and how her viral load has become undetectable. Martha's viral load has remained so low that it has gone undetected for the last few years. Martha recently found out that she is expecting a baby, and, while she is excited to tell Ibrahim all about it, she is also very nervous. She speaks to her friend, Shahida, who she met at the health care facility and who has a one-year-old daughter, Mercy. Martha shares her experience of living undetectable but also her concerns for her baby and her growing family. Later, she tells Ibrahim the news, and they speak about their situation.

MARTHA AND IBRAHIM



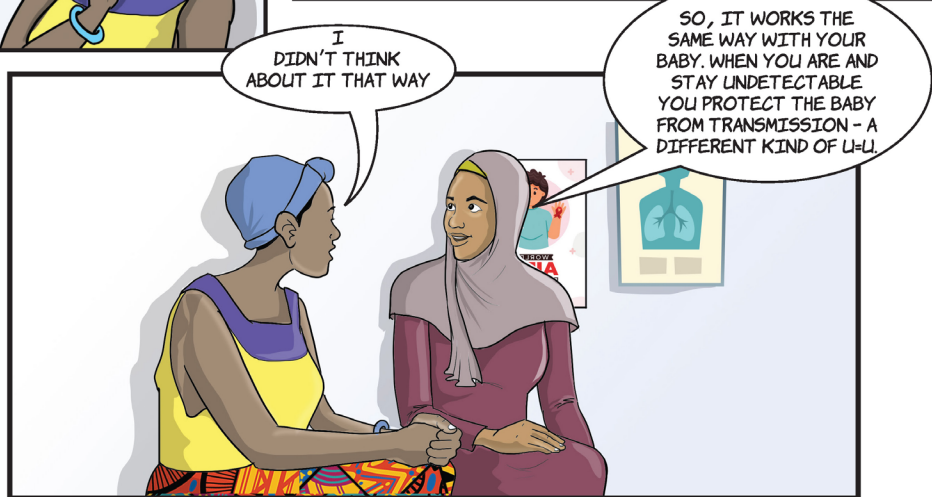
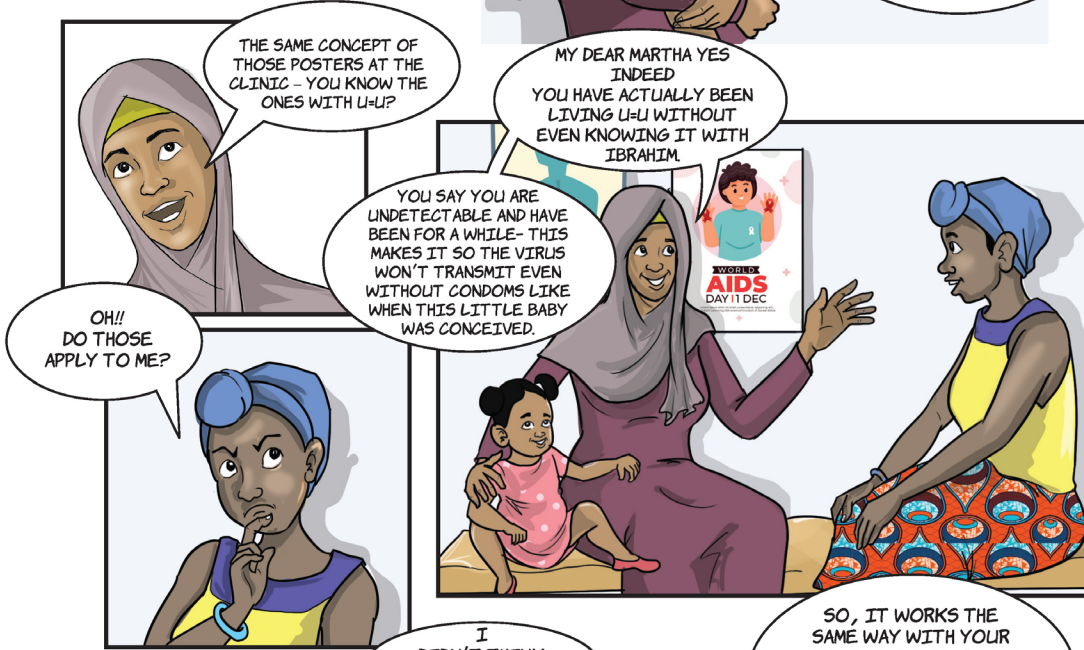
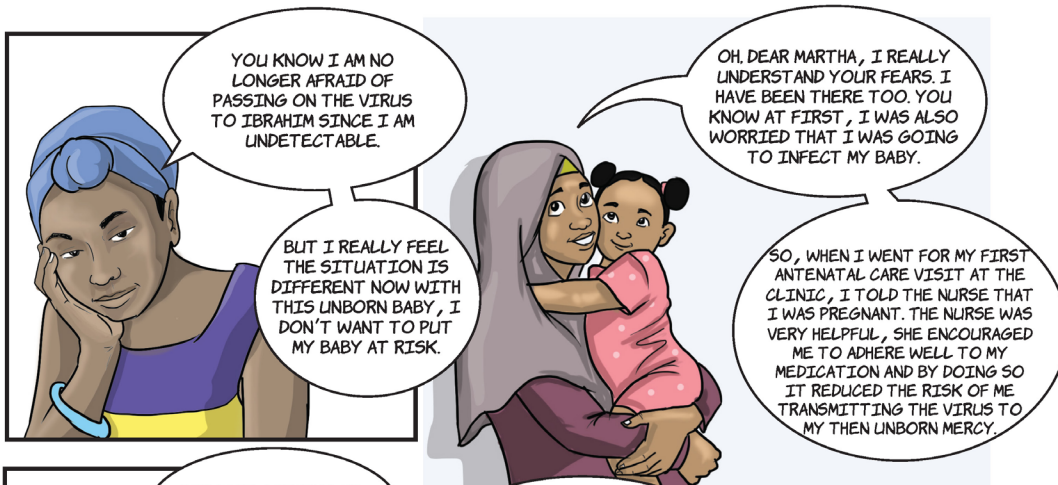
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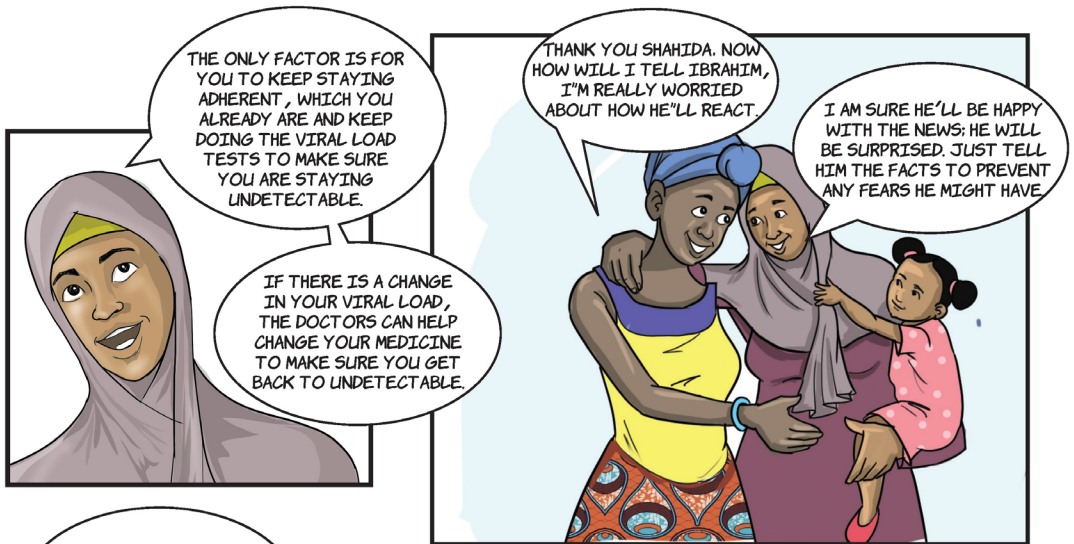
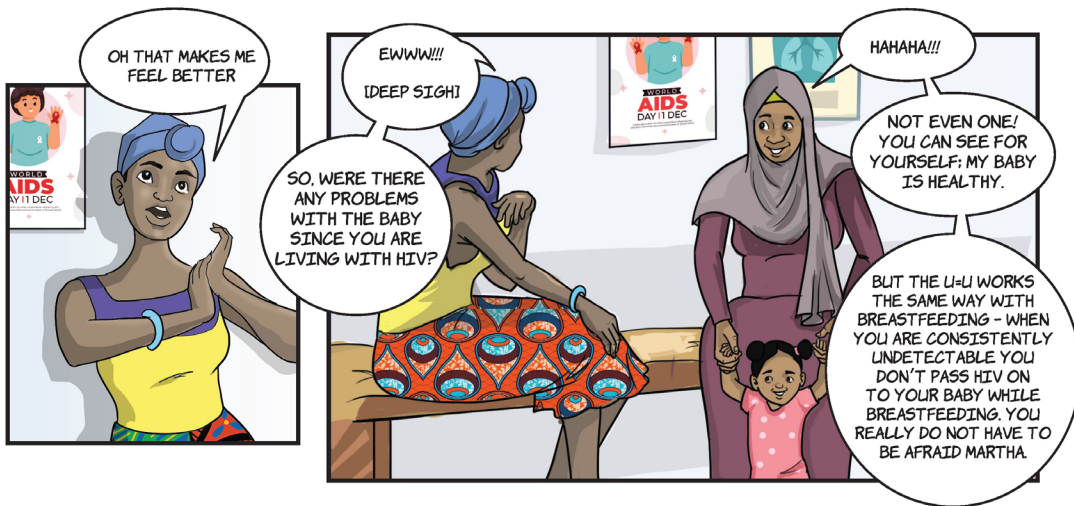


UK Research
and Innovation

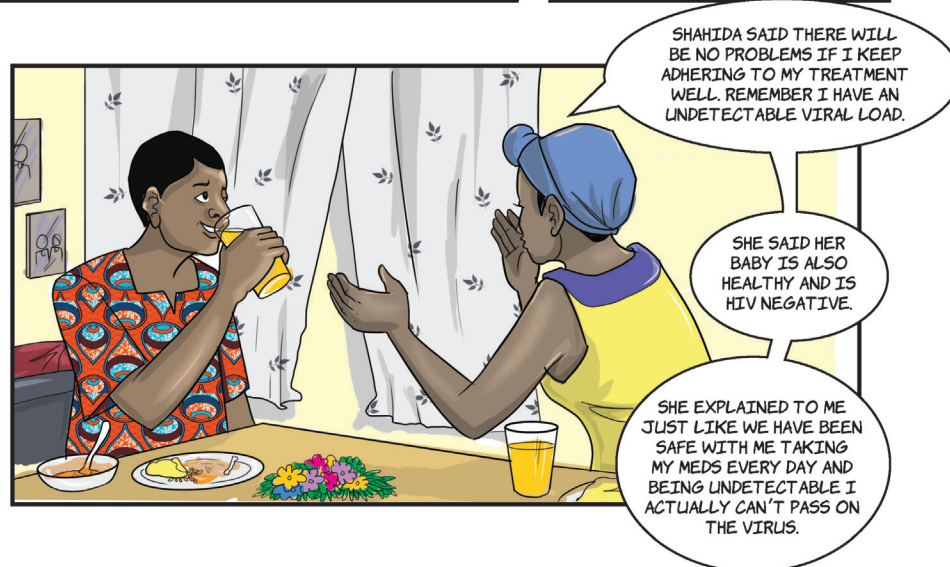
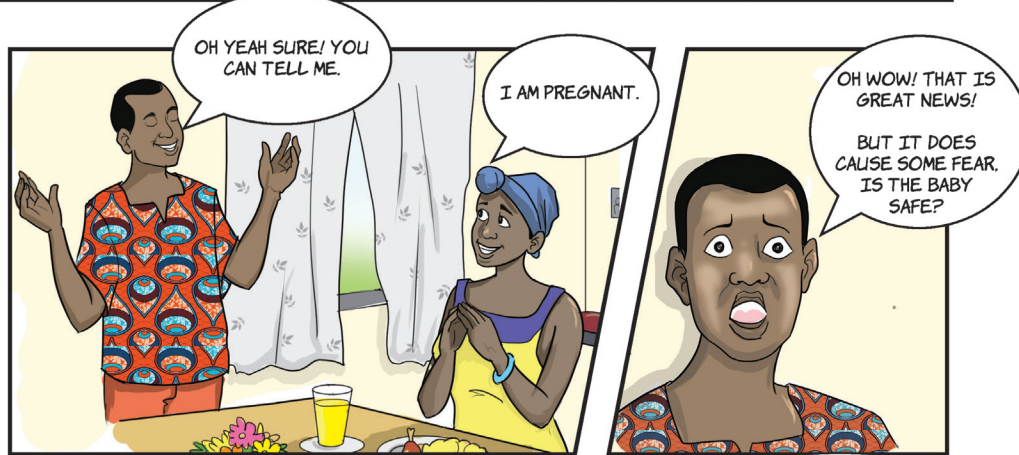


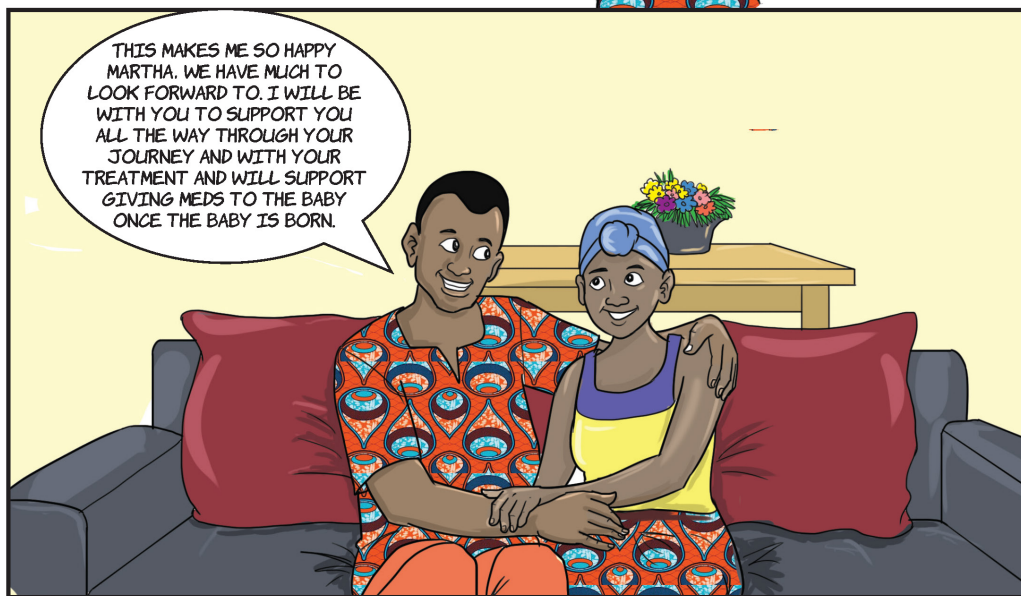
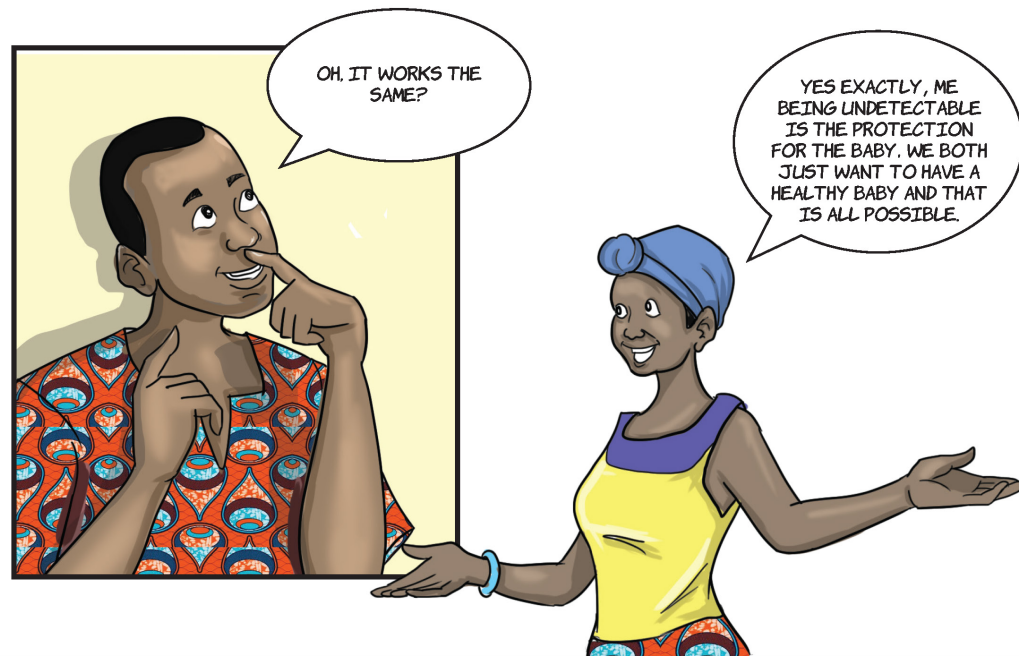
Illustrated and designed by
**Urithi
STUDIO**
www.urithistudio.com





LATER IN THE DAY DURING DINNER AT HOME MARTHA SHARES THE NEWS WITH IBRAHIM





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Illustrated and designed by:



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

1. What happened in the story?
2. Why did Martha want to seek Shahida's advice?
3. Did you learn anything from what Shahida shared? If so, what?
4. Does Martha have any reason for concern or fear for the health of her baby?
5. How does Martha explain not needing to be afraid of transmitting HIV to the baby while talking to Ibrahim?
6. What are some of the things Ibrahim can do to support Martha?
7. How does U=U apply to this scenario with Martha?
8. How was it explained that U=U and prevention-of-mother-to-child-transmission (PMTCT) of HIV are connected?
9. How does Martha being undetectable protect the baby and Ibrahim?
10. Has anyone been — or know anyone who has been — in a scenario similar to this? Were there any similarities in the story and your or your peer's experience?
11. What are the key takeaways from this story? Did you learn anything?

Key takeaways from the story:

- ✓ People living with HIV can have normal, healthy, full lives — including meaningful relationships, getting married, and having children who are HIV-negative
- ✓ 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
- ✓ U=U applies to PMTCT — in safe pregnancy, birth, and breastfeeding
 - *There is a different threshold for preventing HIV transmission during pregnancy/birth/breastfeeding of 50 copies for a viral load (compared to the U=U <200 copies level), which is because the baby is in such close contact with the mother all the time*
- ✓ U=U is a powerful concept for protecting a partner and baby

Key terms from the story:

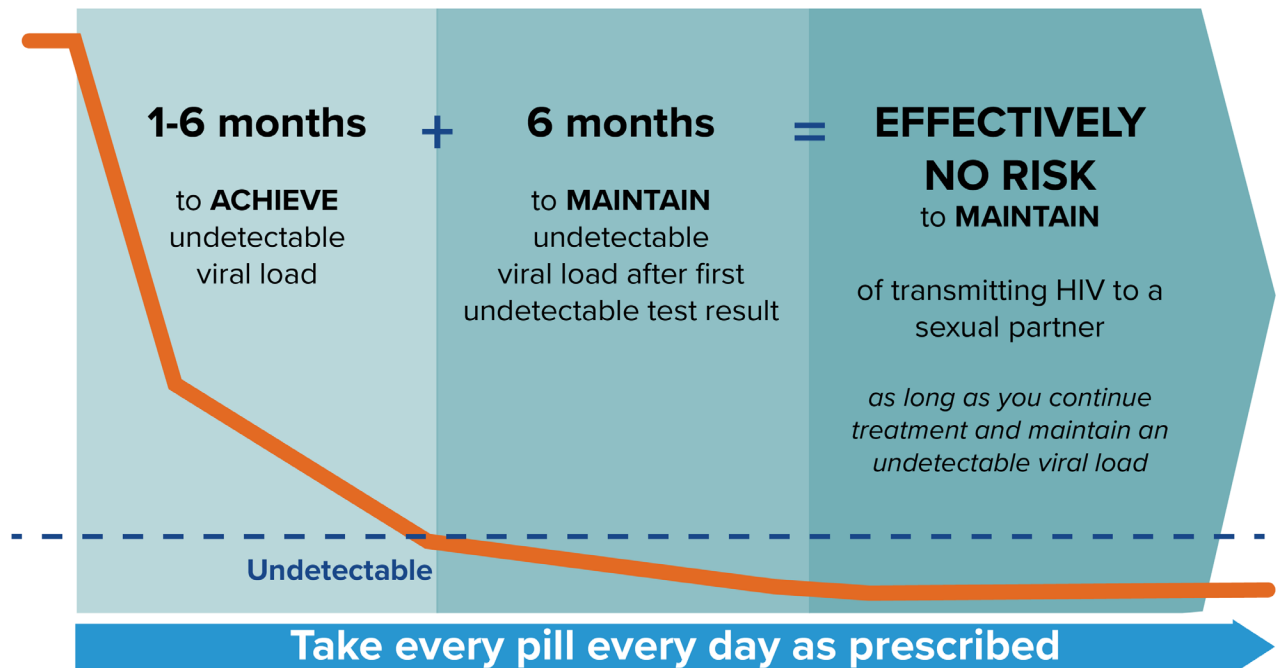
- Being suppressed: this is when someone who is living with HIV's viral load is under a certain level (less than 1,000 copies), which is a great accomplishment and comes from correctly taking the medication consistently and daily.
- Being adherent: this means being consistent in taking your medications as prescribed and discussed with your health care provider. Being adherent helps the medication work as it is supposed to in fighting HIV and helping the healthy cells in your body increase to lower your viral load.

Potential questions and responses

Potential questions/confusions	Responses
<p>What if I found out I am HIV-positive after I found out I am pregnant?</p>	<p>The first step — if it has not already been completed — is to be initiated on ART and linked to antenatal care and PMTCT at the health care facility. The best way to protect your baby is to take the medication (ART) prescribed to you by your health care provider consistently and daily. After your baby is born, the health care providers will test your baby for HIV at different times to make sure they give the right medication for your baby and to make sure your baby stays healthy. The health care providers will also offer you medication that is given to babies potentially exposed to HIV while still in the uterus. This medication can decrease the risk of transmission. In addition to the prevention medication, it is critical to keep taking your medication to protect you and the baby in postpartum and during breastfeeding.</p> <p>U=U would not be applicable in this case because, for PMTCT, we are using a much lower threshold of viral load (less than 50 copies per milliliter of blood). For U=U to be applicable in your relationship, you would need to have started ART before conception and achieved and sustained viral load suppression throughout the pregnancy. As a frame of reference, U=U is usually valid when someone has achieved and been virally suppressed for over six months. <i>[see figure below]</i></p>
<p>What if I am HIV-negative and pregnant but my partner is HIV-positive and undetectable?</p>	<p>If your partner is undetectable and has been consistently undetectable for over six months, the virus would not be transmitted to you or the baby — this is the U=U scenario of the story just with the other partner living with HIV.</p> <p>PrEP is also an option that may be available. You can start and take PrEP throughout pregnancy and breastfeeding without any harm to the mother or baby.</p>
<p>If I am undetectable, why does my baby still have to get prevention medication after being born?</p>	<p>All babies that were potentially exposed to HIV in the uterus are tested when born and receive this medication that is a precaution to reduce any risks.</p> <p>While undetectable means not transmitting HIV to a sexual partner, the baby, being in the womb for a long time, needs to be tested after birth to confirm that no transmission occurred. The viral load level is lower for preventing transmission while pregnant (50 copies) compared to the 200 copies for U=U as the baby is in constant contact with the mother and her body, so the exposure is closer and is prolonged.</p>

Do I need to test my viral load more than once during my pregnancy?

Yes. Usually, a viral load test is taken during pregnancy and breastfeeding to monitor any changes in your viral load. A viral load test is done more frequently — every three months — during pregnancy to make sure that any rise in viral load is noticed quickly in order to respond and reduce the risk of transmission to the baby.



Adapted from original graphic by National Institute of Allergy and Infectious Diseases (NIH)

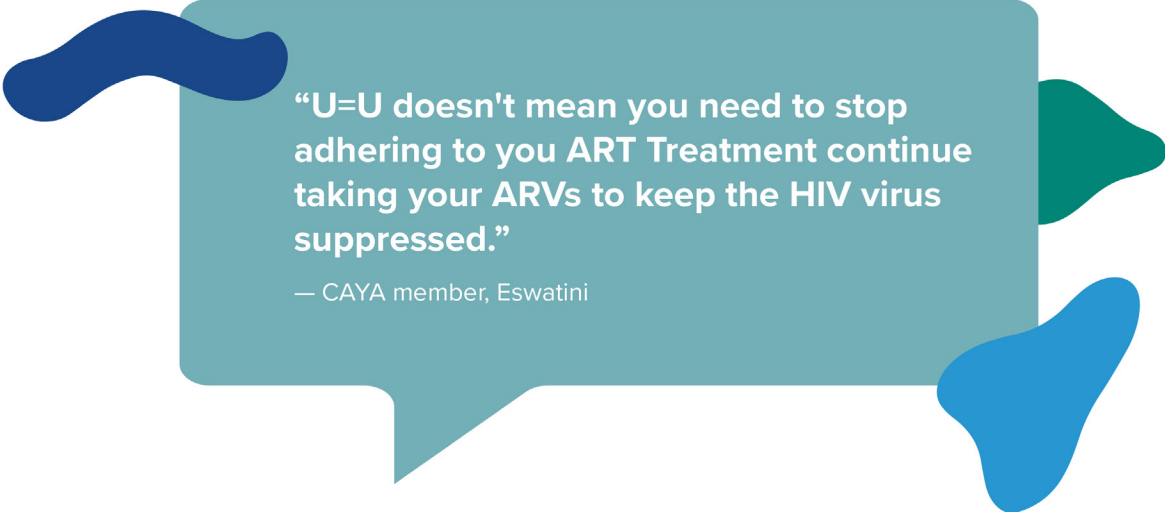
Figure 2. U=U Figure²

² <https://aidsresource.com/treatment-as-prevention-campaign/uisu/>

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.



“U=U doesn't mean you need to stop adhering to you ART Treatment continue taking your ARVs to keep the HIV virus suppressed.”

— CAYA member, Eswatini



“Taking your medication well or good adherence leads to a good or fulfilling life.”

— CAYA member, Eswatini

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 (<i>double bagging</i>) provides more protection against STIs/STDs	<i>False</i>	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	<i>False</i>	Only condoms prevent both STIs/STDs and pregnancy
Using an oil-based lubricant or Vaseline with a condom can cause holes	<i>True</i>	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.	<i>True</i>	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	<i>True</i>	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	<i>False</i>	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	<i>True</i>	Yes, sex is meant to be pleasure for both people.
You can have an STI/STD without knowing it or having any symptoms	<i>True</i>	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	<i>False</i>	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	<i>False</i>	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	<i>False</i>	A girl who is menstruating can get pregnant any time a couple has unprotected sex.
The HPV vaccine is only for women	<i>False</i>	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)	<p>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.</p> <p>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.</p>
Pre-exposure prophylaxis (PrEP)	<p>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.</p> <p>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.</p>
Human Papilloma Virus (HPV) vaccine	<p>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 sexually active.</p> <p>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.</p> <p>By getting vaccinated, you can protect yourself against the virus, as well as your sexual partners.</p>
U=U	U=U stands for <i>undetectable equals untransmittable</i> . 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
1 Someone who is HIV-negative had sex with someone and the condom broke and neither of them knows the HIV status of the other	<input type="text"/> Condoms
2 A person usually has sex with multiple people and doesn't always use a condom	<input type="text"/> Contraception
3 This couple wants to wait to have children and just want to enjoy each other's company for the time being	<input type="text"/> PEP
4 One person in a couple is living with HIV and has an undetectable viral load and the couple has sex without using a condom	<input type="text"/> PrEP
5 When a guy wants to keep his partner and himself safe from both STIS and pregnancy, he will use this	<input type="text"/> U=U
6 When a guy wants to build immunity to the human papilloma virus which can cause cancers in both men and women	<input type="text"/> HPV vaccine

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.

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

