ECOM

# HOW TO TALK ABOUT HIV AND PREP

## RECOMMENDATIONS FOR NGO COMMUNICATIONS TEAMS

2025

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The topic of HIV remains challenging for open discussion. It's not only about medicine—it also involves social prejudice, stigma and discrimination that directly affect the lives of people living with HIV. Any message on this subject can evoke a wide range of emotions—from anxiety to resistance. That's why it's especially important for human rights organizations and communications specialists to pay close attention to wording, tone and context.

In this guide, we'll explore how to talk about HIV on social media: how to explain complex things in simple language, how to avoid stigmatizing people, and at the same time share important and useful information. This not only increases awareness but also helps change public attitudes toward HIV.

It's especially important to find your own approaches to each topic. Our examples are based on a sex-positive and trans-inclusive approach, but we encourage creativity and adaptation of materials for specific audiences.

# TOPIC 1. WHAT IS HIV

HIV is the human immunodeficiency virus. It attacks immune system cells, destroying them or disrupting their function. Over time, the immune system becomes weakened and can no longer protect the body from infections and diseases. People with immunodeficiency become vulnerable to a wide range of infections, certain types of cancer and other illnesses known as opportunistic diseases.

AIDS is the acquired immunodeficiency syndrome. It's caused by HIV infection. Without treatment, most people living with HIV develop AIDS symptoms after an average of 8-10 years.

HIV is found in blood, semen, vaginal fluids and breast milk.

HIV is transmitted sexually, through shared needles and syringes, through unscreened blood transfusions, and from mother to child.

## RECOMMENDATIONS FOR COVERING THE TOPIC

Many people believe they know the basics about HIV, but in practice, people still get confused and make mistakes. Therefore, instead of emphasizing what's «important to know,» encourage your audience to test their knowledge. This can be done, for example, through quizzes in Instagram Stories or Q&A posts: one slide contains a question and possible answers, the next displays the correct answer and explanation. Ask your followers to share their results in the comments and replies.

HIV is most often mentioned on December 1, World AIDS Day. But it's important to talk about it not only on that day but throughout the year. Look for local and global occasions to remind your audience of the key information about HIV.

Don't forget to use correct terminology. Refer to the UNAIDS Terminology Guidelines and keep in mind that different regions may have their own language recommendations regarding HIV.

# TOPIC 2. WHY HIV STILL HAS NO CURE

In 1984, U.S. Secretary of Health Margaret Heckler announced that a medicine for HIV would be available within two years. Yet, forty years later, it still doesn't exist.

The reason for this is that the virus is extremely complex: it replicates rapidly, constantly mutates and creates numerous genetic variants that our immune system can't handle. As a result, potential drugs and vaccines haven't yet undergone full clinical trials. Most studies stopped at early stages, some are still ongoing.

Cases of cures often reported in the media are linked to stem cell transplants from donors with a rare mutation that blocks the virus from entering cells. However, this procedure is too risky and expensive to become a widespread solution for nearly 40 million people living with HIV.

Today, antiretroviral therapy remains the primary tool: it controls viral replication and allows people to live full lives.

Therefore, it's important to get tested regularly—at least every six months—and, if the results are positive, start treatment as early as possible. Modern medications can help maintain health and vitality for many years.

## RECOMMENDATIONS FOR COVERING THE TOPIC

In recent years, results of studies have been actively picked up by the media. We recommend periodically monitoring such news via search engines— just select materials from the past month. For example, in June 2025, scientists reported a new step toward developing a cure for HIV.

Complex scientific information should be explained as simply as possible, and texts should be reviewed by friendly specialists before publication to avoid mistakes. Always emphasize: regardless of HIV status, every person has the right to respect and a dignified future.

# MYTHS ABOUT HIV INFECTION

## MYTH: HIV AND AIDS ARE THE SAME THING

In fact, they're different. HIV is the virus that causes the disease, while AIDS is a stage of the illness. Unfortunately, many people still confuse the two. For example, in the 2025 film Weapons, one of the characters injures himself with several syringes. In the next scene, he asks another character who had used those syringes, "Do you have AIDS?" It would've been more accurate to ask, "Do you have HIV?" since the virus can be transmitted not only at the AIDS stage.

## MYTH: PEOPLE WITH HIV DIE YOUNG

HIV can remain asymptomatic for a long time, but without treatment it leads to AIDS and serious consequences. Today, antiretroviral therapy allows people living with HIV to live full and healthy lives. For example, in the TV series How to Get Away with Murder, one of the characters takes a test and finds out he has HIV. He starts treatment, dates his partner for a long time and later marries him.

## MYTH: HIV IS A GAY DISEASE

In the early 1980s, the disease was called GRID (gay-related immune deficiency). Later, it was discovered that people of any sexual orientation or gender identity can be at risk. Unfortunately, some public figures still claim that HIV infection is a disease that affects only gay men. For example, in 2021, rapper DaBaby said on stage: «If you didn't show up today with HIV/AIDS, or any of them deadly sexually transmitted diseases that'll make you die in two to three weeks, then put your cell phone light up. Fellas, if you ain't sucking d— in the parking lot, put your cell phone light up." His words caused a scandal: the fashion brand BoohooMAN ended its collaboration with him, his performances were canceled, and radio stations stopped playing the Levitating remix featuring him and Dua Lipa.

## RECOMMENDATIONS FOR COVERING THE TOPIC

Use our examples from pop culture to make your texts more engaging and relatable to your audience.

# PUBLIC FIGURES LIVING WITH HIV

## 5 HIV-POSITIVE CELEBRITIES OF OUR TIME

### JONATHAN VAN NESS

The host of Queer Eye on Netflix learned about his HIV status at the age of 25. For a long time, he kept the diagnosis secret, but in 2019 he decided to speak about it publicly. “It gave me a reason to really fight. I absolutely do not think I’d have been as socially aware or conscious [without it],” Jonathan said in an interview.

### GREG LOUGANIS

One of the greatest divers in history who’s considered a sports legend. In 1988, he found out he was living with HIV—just six months before the Olympics. That didn’t stop him from winning a gold medal. Today, Louganis is involved in charity work and appears on sports TV shows.

### OLIVER SIM

The musician has been performing for years as part of the band The xx, best known for their hit Crystalised. In 2022, he released his solo album Hideous Bastard. In the title track, Sim sings, “Been living with HIV since seventeen.”

### BILLY PORTER

The actor took an HIV test in 2007, and the result came back positive. Thanks to therapy, he continued a successful career. In 2018, Porter began starting in the TV series Pose, which explores, among other things, the topic of HIV. For this role, he received nominations for the Golden Globe and Emmy Awards.

## ANDY BELL

The vocalist of Erasure revealed his HIV status in 2004. He continues to tour and record new albums. “Some of my fans said I wouldn’t live long. It feels good to be living proof that they were wrong,” Bell said in an interview.

## RECOMMENDATIONS FOR COVERING THE TOPIC

Here are a few more public figures who have openly shared their HIV status: actor Charlie Sheen, basketball player Magic Johnson, designer Mondo Guerra, politician Kevin McKenna and rugby player Gareth Thomas. Their stories show that it’s possible to live fully, love and make plans for the future with the diagnosis.

When we write and talk about people living with HIV, this complex and taboo topic becomes closer and easier to understand. Most of them emphasize the importance of regular testing—use this to remind your audience to take care of their health.

# 5 HIV-POSITIVE CELEBRITIES OF THE 20TH CENTURY

## ROCK HUDSON

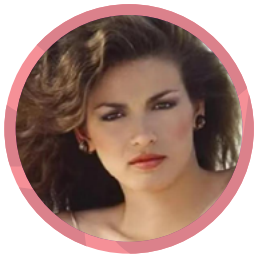
One of the leading actors of Hollywood's Golden Age. Hudson learned of his diagnosis near the end of his career—in 1984. He continued to work until his strength gave out completely. He became the first popular actor to publicly disclose his illness.

## FREDDIE MERCURY

He is still considered the king of rock music. In the early 1980s, he was diagnosed with HIV. Despite deteriorating health, he continued to tour and perform with his band. In November 1991, he officially confirmed his HIV status and passed away the following day at the age of 45.

## RUDOLF NUREYEV

A choreographer and ballet dancer who became world-famous. In 1961, after touring in Paris, he chose not to return to the USSR, becoming one of the most famous "defectors." In 1984, he was diagnosed with HIV. The disease gradually progressed, and in 1993 Nureyev died from complications.



## GIA CARANGI

One of the first women in the fashion world to be called a "supermodel." In 1983, Carangi began treatment for addiction, but after leaving the modeling business, her career came to a halt. In 1985, she was diagnosed with AIDS, and the following year she passed away.

## ISAAC ASIMOV

The writer was often called "the father of modern science fiction." He contracted the virus because of a blood transfusion he received during heart surgery. At that time, HIV couldn't yet be detected in donated blood. His diagnosis was kept secret for many years—his family revealed it only ten years after his death.

## RECOMMENDATIONS FOR COVERING THE TOPIC

When writing about famous people who died of AIDS, remind your audience that science has advanced greatly since then, and today people living with HIV can lead full, healthy lives thanks to therapy.

# 5 HIV-POSITIVE DRAG QUEENS

## ONGINA

Ongina came to international attention after the first season of RuPaul's Drag Race. In one of the episodes, she openly shared her HIV-positive status—and never regretted it. "It changed my life drastically because it was a weight lifted off my shoulders. It also became an inspiration for others to live out loud about being HIV positive," she says. Today, Ongina takes part in social campaigns and advocates for people living with HIV.

## Q

Q from Kansas became famous after participating in Season 16 of RuPaul's Drag Race. She revealed that she's HIV-positive in order to help break the stigma and fear surrounding the virus. Now, Q inspires others and shows that it's possible to live a full life with HIV.

## CONCHITA WURST

After winning the Eurovision Song Contest, Thomas Neuwirth learned of his HIV status during a medical checkup. He told his close friends and began treatment, but an ex-partner tried to blackmail him. Thomas then took a brave step and spoke about it publicly. Today, the artist continues to record albums, appears in films and reality shows and performs around the world.

## CHARITY KASE

The BBC described her as "one of London's most extravagant drag queens." Charity learned of her diagnosis at the age of 18. Her love for bold and unconventional fashion helped her overcome depression. "I think my experiences came out in my aesthetic. I like weird, spooky things," the performer says.

## BARBIE BREAKOUT

She hosts the German version of RuPaul's Drag Race. "Being open and honest is incredibly empowering. I always say that HIV made me kind of 'blackmail-proof,' if I can put it that way," she said. She's been living with HIV for over 20 years.

# 5 HIV-POSITIVE ADULT FILM ACTORS

## ROCCO STEELE

He entered the adult film industry at the age of 40 and has worked there for almost two decades. Over this time, Rocco has received numerous awards and public recognition. He speaks openly about his HIV status and emphasizes that thanks to therapy, he feels great.

## BOOMER BANKS

Designer, activist and adult film star. In the early 2000s, he was using injection drugs and learned about his HIV status during that time. Today, Boomer is at the peak of his career, enjoying life and actively advocating for the acceptance and support of people living with HIV.

## BROCK BANKS

No, he's not related to Boomer—though he always admired him and chose a similar stage name. Brock has never hidden his diagnosis, which is why major studios often refused to work with him. He's had to explain that a person on antiretroviral therapy can't transmit the virus to a partner.

## KAYDEN GRAY

In 2017, Kayden posted a touching video on YouTube, where he shared how he learned about his HIV status. The diagnosis was a shock to him at first, but he started therapy and now actively encourages others not to delay treatment.

## JACEN ZHU

He found out about his diagnosis at the age of 16. Dreaming of fame, Jacen entered the adult film industry, but in 2017, he turned down work at major studios because of racist scripts. Today, he develops his social media presence and participates in campaigns supporting people living with HIV.

## RECOMMENDATIONS FOR COVERING THE TOPIC

The adult film industry is a controversial topic within the human rights community—we recommend reminding your audience of this. Emphasize that the experiences of people living with HIV are diverse, yet all of them matter.

# 5 PUBLIC ALLIES OF PEOPLE LIVING WITH HIV

## PRINCE HARRY

His mother, Diana Spencer, supported people living with HIV, and today Harry continues her legacy. In 2016, he took an HIV test live on air, and thousands of viewers followed his example. “We need to know our status in order to make other people’s lives safer,” Harry said.

## CHARLIZE THERON

In 2007, the actress founded her own charity to support people living with HIV. Over ten years, the foundation raised more than six million dollars. And in 2024, Charlize handed over her Instagram account to activist Ibanomonde Ngema so that millions could hear her story and learn more about the condition.

## MADONNA

The pop queen has been speaking about HIV since the early years of her career. Back in 1989, in the booklet for her album Like a Prayer, she reminded fans of the importance of safe sex. And in 1992, she released the song «In This Life» about a close friend who died of AIDS at the age of 23. Madonna continues to address the epidemic in her work and at charity events.

## BARACK OBAMA

During his presidency, millions of people gained access to antiretroviral therapy. The Obama administration supported HIV prevention research, including PrEP, and funded vaccine development. Today, Obama continues to support people living with HIV through his foundation.

## ELTON JOHN

The legendary musician founded the Elton John AIDS Foundation, which funds testing, prevention and treatment programs in dozens of countries. Thanks to Elton’s efforts, hundreds of thousands of people have gained access to therapy and support.

# FILMS ABOUT PEOPLE LIVING WITH HIV


## PHILADELPHIA, 1993

Young lawyer Andrew Beckett is fired from his firm because of his HIV status. To defend his rights, he decides to sue the company—but no attorney is willing to take his case. Tom Hanks won an Oscar for this role, and Philadelphia became one of the first major films to address homosexuality and HIV.


## DALLAS BUYERS CLUB, 2013

A Texas cowboy learns about his diagnosis, and doctors predict he only has a month to live. But he refuses to give up—he begins smuggling medications together with his friend Rayon. Matthew McConaughey and Jared Leto both received Oscars for their performances, although the casting of cisgender actor Leto as a transgender woman sparked controversy.


## THE NORMAL HEART, 2014

The story takes place in the early 1980s in New York, when the AIDS epidemic was just beginning. Several activists try to draw public and government attention to the new disease. The film was released on HBO and won several television awards.


## 120 BEATS PER MINUTE, 2017

Based on real events, the film tells the story of the Paris-based organization ACT UP, which fought for the rights of people living with HIV in the 1990s. The film won four awards at the Cannes Film Festival and four César Awards.

## THREE MONTHS, 2022

Pop star Troye Sivan plays Caleb—a young man waiting for his HIV test results. The wait makes him rethink friendship, support and the value of close people.

## RECOMMENDATIONS FOR COVERING THE TOPIC

Many of these films are based on true stories and played an important role in raising awareness of HIV. However, keep in mind that they sometimes contain outdated or inaccurate language, as well as misconceptions about the virus itself. They're worth watching, but it's important to consider the historical context in which they were made.

# TV SERIES ABOUT PEOPLE LIVING WITH HIV

## HOW TO GET AWAY WITH MURDER, 2014

In the past, whenever a character in a TV show was HIV positive, the whole plot revolved around their diagnosis. Here, things are different. Oliver Hampton is, above all, a smart and talented programmer who can find anything online. Viewers loved him so much that he quickly went from a secondary character to one of the main ones.


## POSE, 2018

In Pose, the topic of HIV is prominent. Several characters live with the condition, and the series honestly portrays the atmosphere of the 1980s, when thousands of people died of AIDS. It's a drama, but also a reminder of what the LGBT community went through at that time.


## IT'S A SIN, 2021

This series brought actor and musician Olly Alexander international recognition. It's a Sin tells the story of three friends caught in the middle of the HIV epidemic in the UK. It's a deeply emotional and personal story. After the show was aired, thousands of people got tested for HIV for the first time.

## AMERICAN HORROR STORY: NYC, 2022

Each season of AHS tells a new story. The eleventh season is stylish, sensual and socially charged. Its plot unfolds in the 1980s around a mysterious virus—and it's not hard to guess the disease.


## FELLOW TRAVELERS, 2023

A love story that spans decades. In the 1980s, the characters find themselves at the very center of the AIDS epidemic. A beautiful, tender and at the same time heartbreaking series that won't leave viewers indifferent.

# A BRIEF HISTORY OF CONDOMS

The history of condoms goes back thousands of years, beginning with prototypes made from dried animal intestines. According to an ancient Greek legend, snakes and scorpions lived in the semen of the cursed King Minos. To avoid harming anyone, he covered himself with a goat's bladder. In reality, ancient Greek and Roman soldiers also used dried animal organs to protect themselves from venereal diseases.

Medieval chronicles mention Jews and Muslims smearing their genitals with tar or onion juice. Renaissance-era practices in Asia were even more extreme: men wore protective "armor" made from shells or animal horns.

In the 16th century, a syphilis epidemic swept the world. Italian physician Gabriele Falloppio suggested covering the penis with pieces of linen cloth soaked in a chemical solution and then dried. But by the 18th century, condoms came under criticism—they were called "immoral," since sex was considered "pure" in society.

The 19th century brought rubber as a material, and the 20th century—latex. Condoms were especially widespread among soldiers during the First and Second World Wars.

In the 1920s and 1930s, condoms gradually became part of everyday life in big cities. They were increasingly used not only to prevent diseases, but also as a method of birth control. Despite this, condoms remained expensive and were still viewed as "indecent" by many social and religious groups.

In July 1981, the first case of AIDS was recorded, and the United States became the first country to actively promote condoms. In 1991, the first commercial aired on TV, and by 1995, condoms could already be purchased online.

The 2000s saw a real boom: condoms became colorful, flavored and even glow-in-the-dark. Today, choosing a comfortable and safe one is easier than ever.

## RECOMMENDATIONS FOR COVERING THE TOPIC

Use international awareness days to remind people about the importance of condoms. For example, this could be Condom Day on February 13 or Contraception Day on September 26. You can also educate your audience about the most common mistakes in using condoms, as well as the 11 "condoms of the future" that received funding from Bill Gates.

# WHAT IS BAREBACKING

Barebacking is the conscious choice not to use condoms. The term is most often used among men who have sex with men. The word bareback originally referred to horseback riding without a saddle. The other meaning appeared in everyday language as early as the 1980s, but it only became widely known in the 1990s.

Why do men choose barebacking? There are several reasons: rejection of condoms; perceiving HIV as a manageable condition; low level of sex education; drug use; the influence of pornography, where unprotected sex is often fetishized. For some, it's also a way to break boundaries and shake up a boring routine.

After the introduction of pre-exposure prophylaxis (PrEP), the topic became even more relevant. PrEP indeed significantly reduces the risk of HIV transmission, but it doesn't protect against other sexually transmitted infections.

In the gay porn industry, condoms were rarely used before the 1980s. In the 1990s, major studios began introducing them—partly on their own initiative, partly under pressure. In the 2000s, some directors tried to "hide" condoms during editing, while others, on the contrary, emphasized them. In the 2010s, some studios abandoned them altogether but added disclaimers stating that actors were tested. In the 2020s, with the rise of OnlyFans, most creators once again turned to content without condoms—this time without any warnings for viewers.

## RECOMMENDATIONS FOR COVERING THE TOPIC

It's important to remind people that today barebacking remains a controversial sexual practice. It can lead to the transmission of other infections, mechanical injuries and the development of antisperm antibodies, which may result in infertility. Importantly, barebacking isn't limited to men who have sex with men: a 2009 study by the New York City Department of Health found that heterosexual women are more likely to engage in anal sex without a condom than gays or bisexuals.

## WHAT IS PRE-EXPOSURE PROPHYLAXIS?

Pre-exposure prophylaxis (PrEP) is the use of medication to protect against HIV infection. PrEP is taken before sexual contact or other risky situations, which is why it's called "pre-exposure." In this context, prophylaxis means preventing infection.

## PREP REGIMENS

Recommendations for PrEP regimens differ between American and European organizations. The Centers for Disease Control and Prevention in the US recommend daily use, as this has demonstrated the highest efficacy. Meanwhile, in Europe, an «on-demand» regimen is acceptable.

In the daily regimen, the medication is taken at the same time every day.

In the on-demand regimen, the medication is taken as follows: the first dose is a double dose 2–24 hours before sex; the second dose is a single dose 24 hours later; the third dose is a single dose after another 24 hours.

Some argue that the on-demand regimen is not suitable for cisgender women and transgender men who engage in penetrative anal/vaginal sex. To ensure concentration levels in tissues enough for protection, PrEP must be taken at least six days a week.

## HISTORY OF PREP

Studies on pre-exposure prophylaxis began in the 2000s. By now, enough evidence has accumulated to consider its effectiveness proven.

The first studies showing that antiretroviral drugs can prevent HIV infection started in the late 2000s. The iPrEx study in 2010 demonstrated that for those who took PrEP regularly, the risk of infection was reduced by 99%. After that, the World Health Organization and the US Centers for Disease Control and Prevention gradually began including PrEP in their official guidelines. In 2012, Truvada was first approved for HIV prevention in the US.

## WHY PREP IS SAFE

Most people who take PrEP medications don't experience any side effects. Fewer than 10% may have mild reactions such as nausea, vomiting or stomach pain, but these usually go away within the first few weeks after starting the medication. Sometimes there are concerns that PrEP might negatively affect the liver. In reality, one of the components of PrEP is also used in the treatment of hepatitis B. That's why it's important to get tested for hepatitis B and make sure the liver is healthy before starting PrEP.

## MYTHS ABOUT PREP

### MYTH: YOU CAN STOP TAKING PREP AND THE EFFECT WILL REMAIN

In fact, PrEP only works as long as a person takes the pills regularly. Once you stop taking them, the protection disappears, and the risk of HIV infection returns to its previous level. The drug has no «cumulative» effect.

### MYTH: PREP PROTECTS AGAINST ALL INFECTIONS

In fact, the drug only reduces the risk of HIV infection. It doesn't protect against other sexually transmitted infections. For these, barrier contraception is needed, such as a condom.

### MYTH: YOU CAN JUST TAKE PREP AND FORGET ABOUT HIV

In fact, it's important to stay in touch with your doctor or social worker and get tested for HIV and other sexually transmitted infections periodically.

## MYTH: ONLY PEOPLE WITH MANY SEXUAL PARTNERS TAKE PREP

In fact, PrEP is suitable for different people. What they have in common is a desire to feel protected and take care of their health.

## MYTH: PREP MUST BE TAKEN LIFELONG

In fact, the medication is prescribed when a person wants to protect themselves from the risk of HIV infection. If a person wishes to stop taking it, they can do so after consulting with a doctor or social worker.

## TRANS PEOPLE AND PREP

It's important to talk about pre-exposure prophylaxis and trans people separately, because this group has its own specific needs and circumstances.

Transgender women are much more likely to be affected by HIV and are often not sufficiently informed about PrEP. It's important to emphasize that PrEP works equally effectively for both trans and cisgender people. Research also shows that there is no interaction between hormone therapy and PrEP.

## LENACAPAVIR

In July 2024, at the International AIDS Conference, the results of clinical trials for the drug lenacapavir were presented. This antiretroviral medication demonstrated nearly 100% efficacy in preventing HIV infection. Moreover, it only needs to be administered twice a year. The World Health Organization has already recommended the use of lenacapavir as a twice-yearly injectable medication, and leading regulators—the FDA and EMA—issued approval in record time.

In 2024, the pharmaceutical company Gilead granted licenses for the production and distribution of lenacapavir in 120 countries, including Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Tajikistan, Turkmenistan, Ukraine and Uzbekistan. In these countries, the drug will be available at a cost of just 40 USD per year starting in 2027.

# PREP CAMPAIGN AND HOW TO ADAPT IT

In 2023, ECOM launched a campaign to promote PrEP among men who have sex with men in the Eastern Europe and Central Asia region. To make the promotional materials more engaging for the community, we drew inspiration from the concept of «Bros,» which is often found in gay stories and other related content.

All visual materials developed within the campaign can be used to inform the community about PrEP. Promotional materials suitable for posts, stories, posters and flyers are available in Russian and English. In addition, selected visuals were translated into seven national languages: Armenian, Georgian, Kazakh, Kyrgyz, Romanian, Tajik and Ukrainian.

Here are some tips on how to adapt the campaign:

- Before publishing, show the visuals and slogans to focus groups to avoid misunderstandings or sensitive topics.
- Determine where your audience is most active—social media, messengers, forums or offline events.
- Collaborate with local friendly organizations and clinics and distribute materials through their networks.
- Monitor the results of the campaign (views, clicks, PrEP inquiries) and share data with colleagues through reports or posts to inspire regional initiatives and improve the campaign.

If you need more information about the campaign, feel free to contact ECOM: contact@ecom.ngo